Appendix 2.

Engagement Analysis Summary

This document is a summary of the engagement outcomes provided by the Consortium of organisations leading the engagement.

“I worry about passing exams and my results - will I be able to do what I want?
There is a lot of pressure around exams/GCSEs
everybody talks about them and I have only just started Y11.
Will I get support at college?
What if I get a job and can't do it?
Will there be help to get a job?
Will I be able to get transport as I don't like buses/crowds?”

“To feel well
I am scared of needles so don't like to go
I just want to stay in bed when I am sick
I don't like to talk to people I don't know
I don't want to take my clothes off at an appointment
Receptionists can ask questions that doctors should ask...
Going to appointments by myself is tricky
Someone needs to see me when I am not well - I can't wait five days because I might be better then
What happens if I go and get bad news?
Will I lose my job if I am ill?”

“I want my own house
I am worried that I may not budget right.
I am worried that I won't find a job and then can't have a house.
Will someone still do my washing, ironing and cooking?
What bills will I have to pay for a house?
Will there be help to understand the forms that I might need to fill in?
What happens if I don't understand a part of the process to get or keep housing?
Can I stay at home?”

“Places can be overwhelming, very noisy and crowded.

My mum always takes me to where I want to go

We usually just game with each other or go to each other's houses

We text and message

I think I get looked at when I go to shops

People don't always understand why I might behave the way I do and say something unkind to me or my parents

I like going on trains and when people are sat in the disabled seats I will tell them they can't sit there - I have a right to them they don't.

Some cinemas have quieter times and it is good to go then

At Alton Towers I can get a fast track ticket

Sometimes I can take someone with me for free

I sometimes think it is just easier to stay at home by myself”

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Report in full

Areas of focus:

8. What else is important to you?

Summary version

1. **What we did and why we did it.**

Introduction

A Learning Disabilities co-production workshop was held earlier this year to think about how to create a new Learning Disabilities Strategy together. It was agreed that a consortium of organisations (Genuine Partnerships, Rotherham Parent Carers Forum (RPCF), Speakup and Guiding Voices) would facilitate activities so that people with living experience can have a voice in the new strategy.

The five focus areas

There were five areas of focus already identified through the Learning Disability Transformation Programme, Transforming Care, South Yorkshire Integrated Care Board (ICB) Learning Disability and Autism Programme, Rotherham's Special Education needs and Disabilities (SEND) Written Statement of Action (WSA) and Preparing for Adulthood workstream, as being important to people with learning disabilities (PWLD), their family/carers and people who are paid to offer them support:

Education

Employment

Housing

Health

Community Inclusion

How the engagement was carried out

We gathered feedback in different ways from as many people as possible:

- Through a survey (electronic and paper)
- In person at RPCF's Disability Fun Day and at Rotherham Show
- We also thought it was important for people with learning disabilities (PWLD) to have the chance to respond through their groups.

We asked *What is important to you?* for each focus area. People could also add other things that are important to them.

We asked PWLD to tell us their age, if somebody helped them complete the survey, and if they also have autism.

Who gave feedback?

In total 249 people participated in the engagement activities, either as part of a group or individually:

17 groups

77 people with LDs (all but 1 with help or as part of a group)

123 people with LDs and autism (all but 5 with help or as part of a group)

17 family/carers

24 people in paid roles (across Education, Health, Social Care, children's and adult services, voluntary/community)

8 'others'

A good range would like to be involved in co-production next steps related to the Learning Disabilities Strategy.

How we organised the feedback

We identified the narratives, or stories, we thought people were telling in their feedback. We thought that this reflected their experiences. The stories we heard seemed to fall naturally under Rotherham's Four Cornerstones of Co-production and Inclusive Practice, where the focus is on trust:

Welcome and Care

Value and Include

Communication

Partnership

How these stories relate to work already happening

Some of the narratives suggest that some of the work that is already taking place in Rotherham is not yet necessarily known, understood or making a difference to people. Some of this work is included in Appendix 2.

It is indicated that there are plenty of positive experiences – but there need to be more.

Feedback from participants about the engagement process: What is important to me?

- Turning this into a longer-term strategy for PWLDs,
- Better quality assurance that takes account of what I say.

"I'm finding that the care companies are not meeting the basic needs of the clients and their voices are not heard when complaining." (practitioner)

- Some PWLD found the questions in the survey hard, even if they had help.
- Include all relevant community organisations.
- More time is needed to genuinely gather voice from the people this strategy concerns, especially from small groups e.g. more work and time is needed to approach children and adults from BAME communities otherwise vital information could be missed.

2. The stories (overarching) of people with learning disabilities/and autism in Rotherham

It is important to me that…

- my basic needs are met: I feel warm, clean, safe, secure and am able to eat healthy food.
- I feel welcomed, included and supported.
- people take the time to get to know me and build up a relationship with me and my family.
- I feel valued and a part of my community.
- I have real choices and opportunities.
- I can be with people I know (friends and family) in familiar places.
- I have enough help to do the things I want to do so that I can be as independent as possible.
- education also helps me learn to be as independent.
- staff are trained so that they have awareness/understanding of my needs.
- support and reasonable adjustments to meet my needs is put in place.
- help comes earlier to stop issues getting bigger.
- there is even more understanding and support for me and my family/carers if I am from a local community that experiences marginalisation e.g. Black, Asian, Ethnic Minority or Refugee (BAMER)
- transport arrangements are better.
- Rotherham feels more inclusive.
- I have a voice.
- I can access any support and/or technology I need for my voice to be heard.
- you communicate with me and my family/carers clearly, when I need you to, and in ways I understand.
- approaches are in place that work for me, planned with me and my family.
- when it is my choice, you will also involve the people who know me best, for example my family/carers, so that they can offer me support if they can (but do not assume they always can)

3. Focus area: Education. What is important to me? (stories that also feature in other focus areas are underlined)

Welcome and care. “Everybody has the right to an education.” (PWLDs/autism) “I want to be welcomed.” (PWLD)	**Value and Include.** “Having a school to go to.” “Less of a culture of believing specialist provision is the only place for young people with SEND.” “I want to do everything everybody else does.”
❖ **Training for staff so that everybody understands me and how to meet my needs.** “Sometimes there is inconsistency in teaching staff and in my support and I feel like I am starting all over again.” (YPWLD/autism) “They have at times physically dragged him. This was due to the staff not having effective training or skills…” (This was shared by a carer within a supportive facilitated group, where the facilitator would have been able to follow up with them). ❖ **Planning for my transitions** “Early transitions work to help young people learn about the new school environment in advance of transitioning.” (YPLD/autism) Having the right people at transition reviews. More support for transition from school to college. More support for PWLD/their families from Black, Asian, Minority Ethic and Refugee (BAMER) communities to understand transitions and what they mean.	❖ **Feeling included**: Relationships and people getting to know me. Empathy and support. ❖ **Supportive, diverse, personalised approaches so the right support and adjustments are in place for me.** ❖ **My EHC is based on my needs, not the provision available .** ❖ **Getting help and support quickly.** Less emphasis on diagnosis for reasonable adjustments to be made/assessments/help when needed/referrals to specialists/assessments being done in a timely manner. ❖ **Making physical, social and mental health as big a priority as academic need** ❖ **Schools and colleges thinking more about my outcomes, life skills, preparing me for getting a job.** ❖ **More specialist provision?**– differences of opinion. ❖ **More opportunities for lifelong learning** “…gap in the service for those with learning disabilities wanting to go on to adult education” [without an EHC] ❖ **Better transport!**

Communicate “Being listened to when I get stressed” YPWLD/autism. “Listen to parents/carers as they know their child the best” (family/carer)	**Partnership** “Having good relationships with school and home – although sometimes we don't like that!” YPWLD/autism
❖ **Having clear information that I can understand.** ❖ **More listening** “My son has a voice but he is not listened to at school.” ❖ **The right technology so that I can communicate easily** (YPWLD/autism) ❖ **Communication with my family/carers** about what is taking place, why it is being done and timescales. ❖ **Communication *within* schools** “I have lost count of the number of times I have been informed my child is absent from school when in fact, the teacher "forgot" to note her arrival. She has permission to arrive 5 minutes later” (family/carer) ❖ **Passing on information about me at transition times** “Provide timetables and information/new teacher details well in advance.” (family/carer) ❖ **My EHC Plan being kept up to date.**	❖ **Having a say:** me and my family/carers should be able to have more of a say about what my provision needs to look like ❖ **A good partnership between me, my family and school/college** ❖ **More understanding of the needs of different families in the local community, especially if they are often marginalised (e.g. BAMER)** “The barriers...are even greater due to various reasons including prejudice, stereotyping, lack of awareness, accessibility, language barriers, assumptions...” Many families have English as a second language (ESOL) or have limited language and this is a barrier as they struggle to communicate with practitioners – this can then cause me and my family/carers to miss out on opportunities to access services. ❖ **More respite for my family/carers** would enable them to consider their own education and training needs; at the moment families have to deal with and respond to issues themselves.

4. Focus area: Employment. What is important to me? (stories that feature in other focus areas are underlined)

Welcome and care.	**Value and Include.**
“We need help, we want a job” (PWLD) “Work is important to people for my self-esteem, well-being, health” (PWLD) “I want to earn money to live a good life” (PWLD)	“Jobs we can do” (PWLD) “The job centre needs lots more training on helping people apply for jobs” (PWLD)
❖ **Having less worry about the future, and work** ❖ **Being welcomed when looking for work, and at the workplace** “Employers need to understand the disabilities and accept people as a part of their team.” (PWLD) ❖ **Independence** Family/carers and schools need to promote independence and have aspirations for me from a young age. ❖ **More jobs for people with disabilities** Egg setting up incentives to have vacancies exclusive to PWLDs, being more flexible about alternative ways of working, understanding employers (what about RMBC and the NHS?) ❖ **The right local support** Inclusive training courses, work experience opportunities, internships and apprenticeships ❖ **Transport** I need to be able to travel to work and back home safely. I need easier access to transport.	❖ **Being valued:** **“**Many people underestimate what autistic people and PWLD can do, especially employers and the jobcentre staff” (PWLD) ❖ **Being supported** to have realistic goals, work towards achieving them, and get employment. ❖ **Having real choices** about work experience, volunteering, jobs. ❖ **Accessible recruitment**: ❖ **Training for staff**: Job centre, job coaches, RMBC, training centre, employers and wider. Learning and development training for employers about the advantages of employing me. Better understanding when I am from minority communities. ❖ **Relationships:** Get to know me ❖ **Reasonable adjustments** Make it easier for me to access work by having a plan in place so that all reasonable adjustments I need are in place. ❖ **Create a financial incentive for me to work but let me build up to it gradually.** The impact of work on benefits needs better understanding.

Communicate "...they started attending Dexx Lifeskills Activity Centre Day sessions in Wath upon Dearne. Here they have access to local employers, attend job fairs, complete work experience and volunteering, they have development plans to get them to be the best they can be and secure paid work" (practitioner)	**Partnership** "I want the chance to work hard and get paid for it" (PWLD)
❖ **Accessible information, signposting and advice.** How to apply to college, get into work and the support I would get; local work experience, internships, apprenticeships and supported employment opportunities; agencies that offer support such as Employment is for Everyone. Clearer pathways and plans. When me and my family/carers are from marginalised communities this information needs to be friendlier and more accessible ❖ **A range of job opportunities are advertised** (not just particular providers) ❖ **Having a database of local employers happy to consider employing me.** ❖ **Support and guidance for employers about how to support me.** ❖ **The technology I need to make communication easy for me should be easily available**	❖ **If I want this, involve people who support me (e.g. my family/carer) at each stage so that they can offer me support when required.** ❖ **At the same time, do not over-rely on my family/carers.** assuming that they will be able to help and support me even though they may have their own needs, so leaving me more disadvantaged. There needs to be more focus on how to empower my family/carers. ❖ **Pay me** I want the chance to work hard and get paid for it. ❖ **Seek feedback, listen** and respond to me/my family/carers. ❖ **Employ more staff from diverse backgrounds.**

5. Focus area: Housing. What is important to me? (stories that feature in other focus areas are underlined)

Welcome and care.	**Value and Include.**
“A clean house in a safe area” (PWLD/autism) “Living in my supported living house with the people I get on well with” (PWLD/autism)	“A couple of people [told us they] are really happy with their current supported accommodation, and ALL said they had never experienced an issue with staff members in their housing scenarios” (practitioner)
❖ **You need to understand that thinking about housing causes me worries and anxieties:** ❖ **Appropriate, affordable housing that I can stay in as long as I wish, whatever my needs** Now, I have to pay more for private rented accessible accommodation, there is a long waiting list (sometimes years), some houses offered are not suitable or accessible for me. There need to be more supported living opportunities when I have complex needs, including assisted living. ❖ **My home feeling welcoming, safe and secure.** ❖ **Friendly face to face support from the council because applying for housing, and managing a house that meets my needs, is complicated and overwhelming.** e.g. a dedicated housing officer for PWLDs. • **Smaller units** e.g. 4-6 apartments (that feel friendlier).	❖ **Support I receive feeling fair.** It is hard to get support if you don’t have a social worker/ considered to have high needs: a lot fall through the gap. There need to be people offering support who can speak the same language as me and my family/carers. ❖ **Living with/close to people I have something in common with, in places I know:** I want to have an opportunity to make friends. Have residents with mixed abilities but not too diverse needs. ❖ **Continuing to have support to develop independent living skills – I want to live as independently as possible.** I want my own space and opportunity/equipment to be as independent as possible. I would like to have support to go into the community. It would be good to have somebody who checks in with me regularly. “Independent living is really, really important and people need to be given the right environment support and opportunity to do so.”

Communicate “[I] want to move out, find [my] own place” (YPWLD) “…understanding their housing benefit can be difficult and many felt their carers/social workers didn't explain things easily enough and used big words they couldn’t understand.” (practitioner)	**Partnership** “I want to be able to pay the rent” (PWLD) “I want to stay at home with my mum and dad while ever it is possible” (PWLD)
❖ **Knowing what the plan in Rotherham is for housing for PWLDs/autism.** ❖ **Having more accessible (easy read) information and advice for me and people who support me.** This needs to be available in schools/colleges. It should include my rights to being independent and the support I need, housing, housing benefit, making choices and where to get help if I need it e.g. for adaptations. ❖ **Discussions about rehousing reaching more people.** so that they do not feel unsupported and isolated ❖ **Understanding the Key Choices website** It is very good but can be tricky to set up:. There needs to be more information for people with disabilities. ❖ **Accessibility of tenancy agreements** ❖ **Communication between tenants and the council being better.** e.g. not putting rent rates up without any notice, or using language too difficult to understand. Easy read is better.	❖ **Empowering people to make choices.** ❖ **Better multi-agency working** to improve communication. ❖ **Employing more staff from diverse backgrounds in housing** ❖ **Addressing the financial barriers to work created by supported housing.** e.g. by applying discount incentives (making work possible without it impacting on where you can live). Help me with paying the bills.

6. Focus area: Health. What is important to me? (stories that feature in other focus areas are underlined)

Welcome and care.	**Value and Include.**
Family/carers can feel they “no longer have a voice after building up respect through lived experiences between the parent and health physician in all departments” until the day before their child turns 18.	“Talk to me NOT my carer.” (PWLD) “Some doctors understand mental health needs. Some health centres are good at understanding how to support mental health needs.” (family/carer)
❖ **People understanding my worries.** ❖ **Making health checks and screening appointments easier/more accessible/consistent (and if I say I want it to happen, involve my family/carers)** Make the Annual Health check automatic for *all* PWLD. 24 hour access to GP/dentist and make it easy to be seen by same GP. People/receptionists to understand my needs and how it can be difficult to attend a place in person. Make clinical appointments less formal, scary and overwhelming/provide more outreach in informal settings. ❖ **It being easier access to specialist support out of the borough if not available here.** • **Quicker diagnoses/access to help** e.g. from Child and Adolescent Mental Health Services (CAMHS) ❖ **More focus on prevention/healthy lifestyle /positive mental health, and opportunities being accessible.** • **The transition between children’s services to adult services needs improvement**	❖ **Making sure people have genuine choices about their health.** ❖ **More recognition of, and quicker support for, mental health issues (although there is also good practice)** ❖ **Friendly, consistent teams that encourage attendance at appointments.** e.g. the specialist team at Badsley Moor Lane ❖ **Review/extend specialist community learning disability services.** ❖ **More training/health education for PWLD, their family/carers *and* around learning disability/autism for those offering support.** “People with some quite complex health presentations are in supported living, or residential placement with staff who have very little training around...physical care needs.../people with a learning disability who may not be able to verbally/or communicate information about their health.” (practitioner) ❖ **Greater accessibility/reasonable adjustments in health settings**

Communicate “They think I can’t think for myself” (PWLD) “Listen to the voice of the parent/carer when the child is non-verbal.. ” (family/carer)	**Partnership** “…where I feel welcome” (PWLD)
❖ **Listening to me and my family about what I need** “Don’t assume I don’t know what you are talking about.” “Listen to the voice of the parent/carer when the child is non-verbal.. ” Make support available so that I feel understood. People need to be trained to understand and ask the right questions of people who aren’t able to communicate and advocate for themselves. “This really matters.” ❖ **Making it easier for me to book appointments for myself and offering me help to do this if I need it.** ❖ **Giving more accessible information** “ a lot of people don't engage with GPs, because they don't give accessible information.” Use pictures, but make them more easy to understand (every word does not need a picture!) Make sure all staff know how to organise a British Sign Language (BSL) interpreter as well as spoken language ones. ❖ **Options/different ways to order medication.** ❖ **Sending multiple accessible reminders about appointments, making clear what the appointment is for**	❖ **Considering the impact of the Annual Health Check** There does not seem to be any quality assurance/they can be quite basic. ❖ **Helping to pay for health-related things like life insurance.** ❖ **Closer partnership working between GPs and voluntary sector organisations.** Familiar community-based organisations could offer spaces for healthcare e.g. community cafés. Funding could be given to smaller groups who could hold health related workshops. GPs could know more about, and make referrals to, voluntary sector organisations.

7. Focus area: Community Inclusion. What is important to me? (stories that feature in other focus areas are underlined)

Welcome and care. “We feel we have many good friends. Most places we go make us very welcome” (PWLDs) “I don’t want to be treated like a toddler” (PWLD)	**Value and Include.** “That we continue to get a choice in our activities” (PWLD) “Finding a partner…having a relationship” (PWLD) “I don’t go out much to meet new people.” (PWLD)
❖ **My experience and worry.** ❖ **Belonging to a friendly, welcoming and caring community where you are valued, that also feels safe.** “Rotherham has some wonderful places to visit and relax. I always feel welcomed.” (practitioner) We need more LD/autism friendly environments. There are many examples of inclusive places/social opportunities that are valued e.g. REACH, Gateway Club, Burlington Bash, Tenacre (Voyagecare), Speakup, Unity Centre training centre, Toby carvery, Gateway pub managed by Mencap. We also need to support family carers to feel more confident. RPCF is highly valued. Some criteria to access groups can make them feel unwelcoming, as though they don’t want me to work with them. ❖ **Recognising and rewarding amazing personal achievements**	❖ **Good specialist and universal organisations providing supportive environments.** e.g. Speakup, Guiding Voices, Gateway, libraries, some GP surgeries, My Place, “Ice Hockey crowd welcome you.” ❖ **Feeling part of a community is important but it is easy to feel excluded.** ❖ **More focus on life skills to support independence.** ❖ **Being able to travel to more places; better transport.** ❖ **More training and awareness raising so that people are more supportive, including staff.** “People sometimes get mad when I am out places because I do things a lot slower” (PWLD) More organisations and businesses need to understand. ❖ **More diverse, affordable local provision** (especially Rotherham Central/North?) ❖ **Being able to access groups that connect you with people you relate to and help you make friends.** ❖ **Having more flexibility, accessibility and reasonable adjustments in specialist and community areas** ❖ **Make being safe in the community is a priority.** ❖ **Having more support for carers**

Communicate “How do you provide support for people who say they don’t need support?” “Sometimes people don’t understand the way I speak and I get upset. But I do my best to communicate in different ways”	**Partnership** “How can we fit in and be accepted in society without feeling different?”
❖ **Information I can understand.** Information about what's happening in my community e.g. types of provision and welcoming spaces; should be easy read. “One main central place that people with additional and learning needs can access to get the help and support needed so they do not have to travel to different areas…they can find it all in one main place.” (family/carer) Many BAMER families are unable to navigate the SCA (Social Care Assessment) service and need this to be understood. There should be accessible bus/train timetables and information. Information about activities could be translated into local community languages/presented on video. ❖ **More people should be helped to have a voice.** ❖ **I only want to tell my story once.** because of the trauma it creates (family carer) ❖ **There is a need for more transparency from services.** ❖ **Awareness raising – change the culture**	❖ **Working WITH us** (not to or for) e.g. when a provider listens to family/person and offers individual adjustments. Stop calling marginalised groups hard to reach; work harder to tackle the racism. Bring people together from different backgrounds. Build a more integrated, cohesive town together. Give funding to smaller community groups who might provide a more bespoke service to support me in my own community, so that I can feel safe to access the activities.

1. What we did and why we did it

Introduction

On the 27th of April 2023 a Learning Disabilities co-production workshop was held involving representation across RMBC Adult and Children and Young People's Services, Health and the voluntary and community sector to consider what would be involved in creating a new Learning Disabilities Strategy together. The following month it was agreed that a consortium of Rotherham-based organisations committed to promoting and facilitating co-production activities, Genuine Partnerships, Speakup, Guiding Voices and Rotherham Parent Carers Forum (RPCF), would begin by facilitating a series of engagement activities with people across the ages with living experience, their family/carers and practitioners they regularly encounter across services. The intention was to ensure them a voice in the new strategy as well as subsequent opportunities to be involved in the identification of priorities and co-producing/reviewing an action plan following publication of the strategy.

The five focus areas

The questions asked focused on areas already identified through the Learning Disability Transformation Programme, Transforming Care, South Yorkshire Integrated Care Board (ICB) Learning Disability and Autism Programme, Rotherham's Special Education needs and Disabilities (SEND) Written Statement of Action (WSA) and Preparing for Adulthood workstream, as being important to people with learning disabilities (PWLD), their family/carers and practitioners with whom they are involved:

Education

Employment

Housing

Health

Community Inclusion

Methodology: how the engagement was carried out

Feedback was gathered in a variety of ways in order to maximise reach *and* enable people with living experience to engage with the focus areas supported by people with whom they were most likely to feel comfortable:

- The consortium of organisations devised an electronic survey that was disseminated to schools, colleges and SEND services, adult services, Health partners and Rotherham voluntary and community organisations. Paper copies were also made available. RMBC re-created the survey on their website and took the survey to Rotherham Show September 2nd/3rd.
- Genuine Partnerships and Guiding Voices engaged participants at RPCF's Disability Fun Day held at Hooton Roberts 18th August 2023.
- £100 was also offered to school/college/LA/voluntary and community groups to facilitate an activity based on a presentation created by the consortium.

Respondents were asked to identify whether they are a PWLD or PWLD and autism, their age group and whether they needed help to complete the survey, a family/carer or a practitioner (and if so, which sector/organisation they represent).

The open question *What is important to you?* was asked for each focus area, with the prompt to think about what is working, not working and what needs to change. The qualitative nature of the open questions was designed to avoid limitations and provide as much agency and scope as possible for the PWLD to have a meaningful voice and include things that are important to them personally. As a result, and there was also an opportunity in the final section for people to add things that are important to them beyond the five focus areas.

Participants: who gave feedback?

- 15 group activities took place, involving 180 people.
  - 65 with a LD
  - 109 with a LD and autism

The numbers in each of the above groups equate to fewer than the total number recorded. It is therefore likely that 6 practitioners and/or family/carers were also involved. One group did not state how many people participated, so 180 is likely to be less than the actual number involved.

Participating groups of young people with LD/LD and autism: Guiding Voices; Newman School (3 groups); Rotherham Opportunities College; Swinton Integrated Resource; BME CYP Group.

Participating groups of adults with LD/LD and autism Speakup self-advocacy (2 groups); CEAD (Community Education for Adults with Disabilities); Lifeskills

Rotherham, Rotherham Keyring; Acres View; Nayi Zindagi; Sandygate Supported Living.

- Electronic survey: 52 respondents (2 via the RMBC website)
  - 2 with a LD (both aged 18-25) 1 with help
  - 8 with a LD and autism (2 aged under 18, 6 aged 26-64) 3 with help.
  - 17 family carers
  - 24 practitioners (Sectors: Education 5 [CYP 4/Adults 1]; Employment/training 2; Health 12; Social Care/Early Help 2; Voluntary/community 3)
  - 1 Blank

- Disability Fun Day 18.08.23 – views captured ‘live,’ all participants with help.
  - 2 more groups completed the survey following the Disability Fun Day (House of Light Trust and one unnamed)
    - → 4 PWLD
    - → 2 PWLD and autism.
  - 3 PWLD completed the survey individually and
  - 2 PWLD and autism
- Rotherham Show – LA representatives continued seeking participation. 1 response was received from the RMBC web survey.
- Genuine Partnerships received 5 individual paper responses:
  - 3 from people with LD (all aged 26-64) with help.
  - 2 from people with LD and autism (aged 26-26 with help).

In total: 249 people have contributed to the engagement activity, either as part of a group or individually.

Including:

17 groups

77 people with LDs – all but 1 with help or as part of a group

123 people with LDs and autism – all but 5 with help or as part of a group

200 PWLD or PWLD and autism

17 family/carers

24 practitioners (across sectors, children’s and adult services, voluntary/community)

8 ‘others’

A good range of PWLD, PWLD and autism, family/carers, practitioners and group representatives have indicated that they would like to be involved in co-production related to the Learning Disabilities Strategy.

Method of analysis: how we organised the feedback

As feedback from individuals and groups was qualitative, a narrative-based approach to identifying the key messages was adopted. Hollway and Jefferson (2000) describe how narratives can be elicited based upon the idea that spontaneous associations acknowledge emotional rather than purely cognitively derived logic. This is an approach that seems most compatible with capturing the fullness of human experience. The researcher is perceived to be integral to the analysis as somebody who is touched by the experience being described. As a result, the messages presented here might be viewed as a co-construction, attempting to move from the researcher being "the highly visible asker of questions to the almost invisible, facilitating catalyst to their stories" (Hollway and Jefferson, 2000, p. 36).

Through the process of analysis, the researcher sets to organise the narratives they identify within the stories being presented. Feedback facilitate through the series of engagement activities seemed to fall naturally under Rotherham's Four Cornerstones of Co-production and Inclusive Practice, where the focus is on trust:

Welcome and Care

Value and Include

Communication

Partnership

How these stories relate to work that is already happening

In part, these narratives reflect a need for better communication about what is happening in Rotherham already. There are some key areas highlighted for further development, but some feedback is also illustrating that some work that is already taking place is not necessarily known or understood by PWLD/and autism, their families and some of the practitioners offering them support.

It will be important to include some information about what is already taking place in the final report (see Appendix 2).

2. The stories (overarching) of people with learning disabilities/and autism in Rotherham

It is important to me that...

- my basic needs are met: I feel warm, clean, safe, secure and am able to eat healthy food.
- I feel welcomed, included and supported.
- people take the time to get to know me and build up a relationship with me and my family.
- I feel valued and part of my community.
- I have real choices and opportunities.
- I can be with people I know (friends and family) in familiar places.
- I have enough help to do the things I want to do so that I can be as independent as possible.
- education also helps me learn to be independent.
- staff are trained so that they have awareness/understand my needs.
- support and reasonable adjustments to meet my needs are put in place.
- help comes earlier to stop issues getting bigger.
- there is even more understanding and support for me and my family/carers if I am from a local community that experiences marginalisation.
- transport arrangements are better.
- Rotherham feels more inclusive.
- I have a voice.
- I can access any support and/or technology I need for my voice to be heard.
- you communicate with me and my family/carers clearly, when I need you to, and in ways I understand.
- approaches are in place that work for me, planned with me and my family.
- when it is my choice, you will also involve the people who know me best, for example my family/carers, so that they can offer me support if they can (but do not assume they always can)

There are plenty of positive experiences – but there need to be more.

3. Focus area: Education

Welcome and care

“Everybody has the right to an education” (PWLDs/autism)

“I want to be welcomed” (PWLD)

What is important to me?

- **Training for staff so that everybody understands me and how to meet my needs.**
  “Sometimes there is inconsistency in teaching staff and in my support and I feel like I am starting all over again” (YPWLD/autism)
  “I've felt like I need to mask my autism to avoid being bullied. Teachers didn't believe I was autistic, so I masked and pretended I wasn't. Teachers paid more attention to people who had very noticeable or severe autism, who could not hide it. Too many teachers don't know how to cater to people's needs.” (PWLD/autism)
  “They have at times physically dragged him. This was due to the staff not having effective training or skills for the people they care for.” (Family/carer)
  - There needs to be better understanding (including in schools) about autism and learning difficulties. LD/neurodiversity is not always visible. (family/carer)
    - E.g. employ practitioners who are neurodivergent to give a presentation talk in schools for a day; one can be dedicated to the children and the other to the adults that support the children. (practitioner)
- **Planning for my transitions**
  “Early transitions work to help young people learn about the new school environment in advance of transitioning.” (YPLD/autism)
  - Have an education (LA) representative at key transition reviews.
  - More support for transition from school to college
  - More support for PWLD/their families from Black, Asian, Minority Ethic and Refugee (BAMER) communities to understand transitions and what they mean.

Value and Include

“...there isn’t enough being done out there for children and young people with LD’s. A lot of assumptions are made about the parents and carers that they will know what to do, what is best for their child and where to send them but more often than not, parent and carers are at a loss. They struggle to keep their families going, let alone look for courses or training they can do in order to help their child who has LD's." Family/carer

- **Feeling included**:
  "Having a school to go to."
  "Opportunity to learn and grow;"
  "Less of a culture of believing specialist provision is the only place for young people with SEND"*
  - Relationships and people getting to know me: "somebody trusted": teachers helping me understand my own strengths and needs/what helps.
  - Teachers helping me understand my own strengths and needs/what helps.
  - Show me empathy and support - rather than assuming I am...
    "Naughty, challenging, disobedient" (Family/carer) and
    "Not having to go to class when you are really upset." (YPWLD/autism)
  - All my achievements are celebrated.
  - There are more resources:
    "special schools are under-resourced and under-staffed."
    "more SEND support" (in mainstream schools).
  - The learning environment is more suited to me/adapted e.g.: smaller classes, better buildings, more outdoor spaces, more visual learning, support worker on site, more flexibility (e.g. around GCSEs and the curriculum), being able to learn at my own pace, sensory support and adjustments, not changing things without preparing me.
    "It can be quite overwhelming to be in classrooms with lots of other children."
    "It can be loud and noisy."
    "I get tired easily."
    "A lot of people need some kind of sensory stimulation, hence why they 'fidget'."
  - I want to do everything everybody else does (including having a right to educational opportunities) to have a fair and equal chance in life:
    - Go on more relevant and inclusive trips.
    - Have a peer group that you have things in common with.

    - More visible, and links with, role models (peers).
    - Change the way exams are delivered, make reasonable adjustments e.g. being able to do exams in a room on our own and having more time to reduce my anxiety.
    - There should be alternative teaching methods to help those of us who are neurodivergent:
      "less emphasis on being so strict with things like uniforms, children should feel comfortable and confident walking into school. They should not have to worry about getting a detention because they forgot to take their coat off before they reached the classroom" (family/carer).
      "Sometimes I find my uniform uncomfortable."
- **Supportive, diverse and personalised approaches to ensure the right support and adjustments are in place for me.**
    - Better differentiation in mainstream schools.
    - Alternative teaching methods.
    - Having regular 'check-ins' with key staff.
    - Giving out paper timetables too rather than having to rely on my phone.
    - Specialist support.
    - Community-based learning.
    - Continuing to focus on my basic skills.
    - More sensory toys (practitioner).
    - Drawing upon art, music and other interests on the curriculum so that I have things I like to talk about.

"Every child should feel safe and supported in school."

"A school that gets my son."

- **My EHC being based on my needs, not provision available.**
    - The EHC process can feel traumatic (family/carer)
    - The provision in my plan needs to be put in place.
- **Getting help and support quickly.**
    - There needs to be less emphasis on diagnosis for reasonable adjustments to be made for me and more access to assessments and help when it is needed/quicker referrals to specialist support/assessments done in a timely manner e.g. my EHC and Annual Review.

- **Making physical, social and mental health as big a priority as academic need**
    - “The catering in the kitchen is nice and healthy” (YPWLD).
- **Schools and colleges thinking more about my outcomes, life skills and preparing me for getting a job.**
  “I went to special school, nothing to prepare me for the world...needed more support” (PWLD).
    - Put more emphasis on life skills and independence in mainstream schools and colleges.
    - Prepare for me getting a job and help me think about/achieve my future goals.
    - Have a house or space where I can practice being independent.
    - Support me to do work placements because a lot of skills can be gained.
    - At school and college there needs to be more cooking, money and maths skills, and practical things like making things, telling the time.
    - Create more educational options related to future jobs and specific careers. e.g., art and craft, masonry, wood working, etc. [vocational skills] (YPWLD/autism).
- **More specialist provision?** (Group of YPWLDs, family/carer)*
    - Mainstream schools are struggling to meet the needs of some young people and there can be a long wait for specialist provision so more specialist provision may be needed so that I feel safe/my anxiety is reduced.
    - Some children feel unable to go to school because their needs are not being met.
    - It would be good if there was a wider option of colleges that will cater for medical needs.
- **Lifelong learning**
  “There is a gap in the service for those with learning disabilities wanting to go on to adult education as once they turn 19 and do not have an EHCP in place they are not eligible for support in Education” (practitioner).
    - I should be able to carry on learning throughout my life.
- **Transport!**
    - Better transport, less time on the bus

*There were different viewpoints, although it could be argued if there was better inclusion, the view that there is a need for more specialist provision might be less prevalent.

Communicate

- **Clear, information I can understand easily:** Teachers and outside speakers need to provide information in a simple way.
- **More listening** Better communication/more listening to me and their family e.g. what assessments are taking place, why they are being done and timescales. What is an EHCP?

  "Being listened to when I get stressed."
  "My son has a voice but he is not listened to at school."
  "Listen to parents/carers as they know their child the best."
- **Technology so that I can communicate easily** (YPWLD/autism)
- **Communication with my family/carers** about what assessments are taking place, why they are being done and timescales.
- **Communication *within* schools**

  "I have lost count of the number of times I have been informed my child is absent from school when in fact, the teacher "forgot" to note her arrival. She has permission to arrive 5 minutes later to avoid the noise and crowds during lesson changes." (family/carer)
- **Passing on information about me at transitions**

  "Provide timetables and information/new teacher details well in advance. Every year we have no schedule until the first day of term and an anxious wait over the summer for my daughter " (family/carer).
- **My EHC Plan being kept up to date.**
  - Ensure all up to date assessments/paperwork are logged in the EHCP so practitioners can access the most recent information.

Partnership

- **Having a say:** me and my family/carers should be able to have more of a say about what my provision needs to look like
- **A good partnership between me, my family and school/college:**

  "Having good relationships with school and home – although sometimes we don't like that!"
- **More understanding of the needs of different families in the local community, especially if they are often marginalised (e.g. BAMER)**

  "The barriers...are even greater due to various reasons including prejudice, stereotyping, lack of awareness, accessibility, language barriers, assumptions etc."

    - Many families have English as a second language (ESOL) or have limited language and this is a barrier as they struggle to communicate with practitioners - this can then cause me and my family/carers to miss out on opportunities to access services.
    - Families/carers often don't know processes or how things work and more needs to be done to raise their awareness. Practitioners often don't often have the right skills/training about my community and due to their lack of understanding can make assumptions.
- **More respite for my family carers** would enable them to consider their own education and training needs; at the moment families have to deal with and respond to issues themselves.

Employment

Welcome and care

"Want to work in a warehouse with people."

"We need help, we want a job." (PWLD)

"Work is important to people for my self-esteem, well-being, health." (PWLD)

"Having a choice with our work placements is important." (PWLD)

"I want to earn money to live a good life." (PWLD)

"It appears to me that there is still a determination to say no before all avenues are explored." (practitioner)

What is important to me?:

- **Having less worry about the future and work:**
  "I worry about passing exams and my results - will I be able to do what I want?
  There is a lot of pressure around exams/GCSEs.
  everybody talks about them and I have only just started Y11.
  Will I get support at college?
  What if I get a job and can't do it?
  Will there be help to get a job?
  Will I be able to get transport as I don't like buses/crowds?"
- **Being welcomed when looking for work, and at the workplace**
    - Staff at job centres need to have more patience and empathy with me when I want to apply for a job.

    - Some workplaces welcome me, and have a good understanding – but there need to be more of these in Rotherham as some people I know have had negative experiences.
      "Employers need to understand the disabilities and accept people as a part of their team." (PWLD)
- **Independence**
    - Family/carers and schools need to promote independence and have aspirations for me from a young age.
    - Schools/colleges need to support the development of independence skills at all ages to help me get a job in the future and be able to manage finances.
    - When I have the opportunity to volunteer, with the right support, I can thrive and flourish.

- **More jobs for people with disabilities**
    - There could be incentives for local employers to set me on e.g. vacancies exclusive to PWLDs, being more flexible about alternative ways of working, understanding employers (including LA/NHS Trusts) who will safeguard, support and protect me.
- **The right local support**
    - Offer inclusive training courses (for example if I am neurodiverse)
    - Offer work experience opportunities.
      "Work experience is important to build confidence and make it easier to get the jobs we want." (PWLD)
    - Offer internships.
    - Offer apprenticeships (with an EHC).
- **Transport**
    - I need to be able to travel to work and back home safely.
    - I need easier access to transport e.g. via grants.

Value and Include

"Make sure that jobs that are offered to young people are suited to the young person and not just any job/something that the young person didn't want to do. "

"Jobs we can do."

"The job centre needs lots more training on helping people apply for jobs." (PWLD)

"There was very little support for my son when he was applying for a job." (family/carer)

“I do believe that there are lots of employment opportunities for people with learning disabilities, but maybe employers are not always set up to offer the additional support that people may need.”

- **Being valued: “**Many people underestimate what autistic people and PWLD can do, especially employers and the jobcentre staff.” (PWLD)
    - Being valued for what I bring rather than what I can’t do.
    - Benefits being in line with pay for working.
- **Being supported**:
    - To have realistic goals and work towards achieving them
    - Get employment e.g. via employment solutions, Speakup, Keyring
- **Having real choices**
    - Equal opportunities e.g. at the job centre. (PWLD)
    - More choice about work experience and volunteering opportunities e.g. in sport.
    - Somebody to help me make those choices.
    - More opportunities for me to try different careers and jobs to make sure it is something I am happy with. (YPWLD)
- **Accessible recruitment**: alternative ways for me to apply for jobs (e.g. easy to read application forms) and have interviews (as needed) : “It would be good if people could send voice message or videos that can give people a chance to say who they are and why they think they would be a good candidate for jobs.” (PWLD)
- **Training for staff**: job centre, job coaches, RMBC, training centre, employers and wider, so that they have the right level of understanding of LDs/autism, and work more pro-actively with people within their local community:
  “Staff/new employers need to understand your learning difficulty well so they can support you well.” (YPWLD)
  “I've had to explain to people how autism affects me as they don't know anything about it.” (PWLD/autism)
    - Learning and development training for employers about the advantages of employing me.
    - Better understanding about my needs/ my family/carers when I am from minority communities as there is stereotyping and assumptions are made, there is also racism; this causes me and my family/carers to turn away from seeking help we are entitled to.
- **Relationships:** Providers and employers also need to be prepared to get to know me, develop a relationship.

- **Reasonable adjustments** Make it easier for me to be able to access work from day one by having a plan in place so that all the reasonable adjustments I need are in place.
    - I have a safe space to go to, I have the equipment I need, I have another worker to talk to
    - Support is easily available and I do not have to find it myself (e.g. a personal assistant, finding three quotes for equipment I need or taxis). (YPWLD)
    - There are more job coaches.
    - There is a local support organisation that is able to check-in and step in and support/mediate for me if there are issues at work (MENCAP can offer support but this needs funding).
    - Make Access to Work available if I work less than 16 hours.

- **Create a financial incentive for me to work but let me build up to it gradually.**
    - It is essential that the impact of work on benefits is clearly explained to me as I would end up in financial difficulty if my JSA (Jobseekers Allowance) or UC (Universal Credit) stopped (practitioner).
    - Make it possible for me to use my personal budget so that I can move from voluntary work to paid work in a way that does not impact on my benefits.

Communicate

- **Accessible information, signposting and advice.**
    - I need help to know how to apply to college, get into work and the support I would get.
    - I need better information about local work experience, internships, apprenticeships and supported employment opportunities and agencies that offer support such as Employment is for Everyone
    - It would be good if this could be made available to me and my family/carers through schools and colleges.
    - When me and my family/carers are from marginalised communities this information needs to be made friendlier and more accessible
    - I need earlier intervention, clearer pathways to work, and plans. "...the only time anyone has talked to them about a paid job is when they started attending Dexx Lifeskills Activity Centre Day sessions in Wath upon Dearne. Here they have access to local employers, attend job fairs, complete work experience and volunteering, they

have development plans to get them to be the best they can be and secure paid work." (practitioner)

- **A range of job opportunities are advertised** (not limited to particular providers).
- **It would be good to have a database of local employers happy to consider employing me.**
  - This could be shared with Health/Social Care/family/carers/groups.
  - It could include supported employment opportunities.
- **Support and guidance is needed for employers about how to support me.**
  - E.g. employers need to understand that communication about changes and big decisions needs to be clear and accessible.
- **The technology I need to make communication easy for me should be easily available.**

Partnership

- **If I want this, involve people who support me (e.g. my family/carer) at each stage so that they can offer me support when required.**
- **At the same time, do not over-rely on my family/carers** – assuming that they will be able to help and support me even though they may have their own needs, so leaving me more disadvantaged; there needs to be more focus on how to empower my family/carers.
- **Pay me** I want the chance to work hard and get paid for it.
- **Seek feedback** listen and respond to me and my family.
- **Employ more staff from diverse backgrounds.**

Housing

"Our home is important." (PWLD in supported living)

"A clean house in a safe area"

"Living in my supported living house with the people I get on well with" (PWLD/autism)

"My family can't move house to keep me safe, there is no houses to move to" (PWLD)

What is important to me?:

Welcome and care

- **You need to understand that thinking about housing causes me worries and anxieties:**
  "I want my own house.
  I am worried that I may not budget right.
  I am worried that I won't find a job and then can't have a house.
  Will someone still do my washing, ironing and cooking?
  What bills will I have to pay for a house?
  Will there be help to understand the forms that I might need to fill in?
  What happens if I don't understand a part of the process to get or keep housing?
  Can I stay at home?" (YPWLD)
- **Appropriate, affordable housing that I can stay in as long as I wish, whatever my needs**
  - I have to pay more for private rented accessible accommodation (e.g. on the ground floor)
  - There is a long waiting list (sometimes years)
    "We have people living with parents at over 40 years of age as a 'temporary' solution until their accommodation is sorted out. This is causing significant distress for some people and impacting their wellbeing and mental health." (practitioner)
  - Some houses offered are not suitable or accessible for me – maybe make grants available for adaptations.
  - The medical priority housing officer in Rotherham was good (reinstate this or a similar, post)
  - There need to be more supported living opportunities when I have complex needs, including assisted living.
  - I can't stay in my home if my health is deteriorating and I need too many adaptations; there should be better planning for my future so I can stay in my home as long as I want to
  - Make the process for applying for adaptations easier, including if I own my own home.
  - Do adaptations in a timely way.
  - Have separate pathways for adaptations for people with different needs.
    - children
    - adults
    - people with life limiting conditions.
- **My home feeling welcoming, safe and secure:**

    - More support is needed if I live in an overcrowded and/or a damp house.
    - There needs to be greater monitoring/quality assurance of housing agencies.
- **Friendly face to face support from the council because applying for housing that meets my needs is complicated and overwhelming** (e.g. a dedicated housing officer for PWLDs, see above)

  "Lots of people still don't use the internet, there needs to be more support available for those people who don't use a computer to apply for housing, we don't want to lose face to face contact with people." (PWLD)
  "Staff who are happy to speak with the person and their family to plan what will work for them" (Family carer)
  "To be told my child doesn't need access to the garden was disgusting. Our initial contact was always focussed on the money and never on the needs of my child or her quality of life." (family carer)
    - Some people have positive experiences of the housing bidding process.
    - Having a named person with a phone number would be helpful – who would work with me think about my disability and the house I need/best area to live in (especially important if I am from a marginalised group)/help to bid/ if I have a problem/I have a repair that needs doing.
    - It is important not to over promise (e.g. say you can impact on an application process when this is beyond your role to do so)
- **Smaller units** e.g. 4-6 apartments (feel friendlier)

Value and Include

- **Support I receive feeling fair.**
    - It is hard to get support if you don't have a social worker/ considered to have high needs: a lot of people fall through the gap.
    - Help seems to go to the people who shout loudest.
    - There need to be people offering support who can speak the same language as me and my family/carers.
    - They need to have a good understanding of local and national policy on adaptations.
- **Living with/close to people I have something in common with, in places I know:**
    - I want to have an opportunity to make friends (e.g. group areas)

    “A couple of people [told us they] are really happy with their current supported accommodation, and ALL said they had never experienced an issue with staff members in their housing scenarios', which we felt was a positive we wanted to share.” (practitioner)

  - In group homes and supported living, have residents with mixed abilities but not too diverse needs.
  - I want to be close to my family.
- **Continuing to have support to develop my independent living skills – I want to live as independently as possible.**
  - I want my own space and opportunity/equipment to be as independent as possible.
  - I would like to have support to go into the community.
  - Have more support workers, but make sure they have understanding and want the role, not make me feel like a burden.
  - It would be good to have somebody who checks in with me regularly, e.g. to make sure that my bills are paid and repairs are done (again, a housing support officer role is suggested, especially important for people who are not computer literate/don’t have access)
  - I want to: “Learn more about cooking and baking.”

  “Independent living is really, really important and people need to be given the right environment support and opportunity to do so.”

Communicate

- **Knowing what the plan in Rotherham is for housing for PWLDs/autism.**
- **Having more accessible (easy read) information and advice for me and people who support me** (see Accessible Information Act)
  - This needs to be available in schools/colleges.
  - It should include my rights to being independent and the support I need, housing, housing benefit, making choices and where to get help if I need it e.g. for adaptations (“Not thought about this” – YPWLD)

“As many of our people don't have very good math skills, understanding their housing benefit can be difficult and many felt their carers/social workers didn't explain things easily enough and used big words they couldn’t understand. Maybe the people who interact with these adults should have further training on communication techniques and how to tailor it to the recipient” (practitioner)

“[I] want to move out, find [my] own place” (YPWLD)

- **Discussions about rehousing reaching more people** so that they do not feel unsupported and isolated.
- **Understanding the Key Choices website**
    - It is very good but can be tricky to set up: "everything being online and some people are not comfortable with this" (practitioner)
    - I sometimes struggle with RMBC website information on housing support, including who to contact and how to find things out.
    - There needs to be more information for people with disabilities.
- **Accessibility of tenancy agreements**
    - The need to be easy to read so that the terms and conditions can be understood.
- **Communication between tenants and the council being better**, for example not putting rent rates up without any notice. It would be good if a letter could be sent out that is easy to read: "People with learning disabilities and autism are on a small budget and putting rates up can easily put people behind with rent." (PWLD)

Partnership

- **Empowering people to make choices.**
  "I want to stay at home with my mum and dad while ever it is possible."
- **Better multi-agency working** to improve communication.
- **Employing more staff from diverse backgrounds in housing**
- **Addressing the financial barriers to work created by supported housing e.g. applying discount incentives** (making work possible without it impacting on where you can live)
    - "I want to be able to pay the rent."
    - Help me with paying the bills.

Health

Welcome and care

"Having our annual health checks and help from our LD nurses" [e.g. at Badsley Moor Lane]

"GP and hospital consultant have been very good with my son."

What is important to me?

- **People understanding my worries.**

To feel well.

I am scared of needles so don't like to go.

I just want to stay in bed when I am sick.

I don't like to talk to people I don't know.

I don't want to take my clothes off at an appointment.

Receptionists can ask questions that doctors should ask...

Going to appointments by myself is tricky.

Someone needs to see me when I am not well - I can't wait five days because I might be better then.

What happens if I go and get bad news?

Will I lose my job if I am ill?" (YPWLD/autism)

- **Making the health checks and screening appointments easier/more accessible/consistent (and if I say I want it to happen, involve my family/carers)**
  - Make the Annual Health check automatic for all PWLD.
  - Provide access to medicine, my GP and dentist when required – 24 hour care.
  - Make it easy to be seen by same GP/have understanding and support me to do so.
  - Have regular check-in surgeries: "being kept up to date with our health."
  - People/receptionists to understand my needs and how it can be difficult to attend a place in person (e.g. go into a waiting room).
  - Make clinical appointments less formal, scary and overwhelming e.g. by having preparation visit opportunities, and more outreach for health checks/blood tests at home or informal settings such as leisure centres so that I feel more comfortable away from intimidating settings.
  - Make it a must that I get longer for appointments.
- **Easier access to specialist support out of the borough if it is not available here.**
- **Quicker diagnoses/access to help** e.g. from Child and Adolescent Mental Health Services (CAMHS)

- **More focus on prevention/healthy lifestyle /positive mental health, and opportunities being accessible.**
    - I should be able to have a healthy lifestyle no matter my needs e.g. more sport and physical activity opportunities like at clubs such as Gateway, sports exercise /camps being open to PWLDs and neurodivergent people through free passes to help the person experience whether the activity is best suited to them or not (PWLD/autism)
    - Disabled facilities at leisure centres and classes
    - Lower cost activities
    - Sessions on family budgeting (to avoid mental health issues that come with debt/poverty and not being able to access healthy lifestyle/activities)
    - More women/girl only facilities; they should be given safe spaces (swimming, gyms); more might attend if they weren't mixed because a lot of women feel self-conscious and can't relax or get involved when facilities are mixed. Muslim women can't attend swimming because of religious reasons and there is only one swimming centre for the whole of Rotherham that offers women only swimming session. This seems unfair because it is ALWAYS packed out and when its full, lots of women are turned away or don't get to attend.
- **The transition between children's services to adult services needs improvement.**
    - Family/carers can feel they no longer have a voice after building up respect through lived experiences between the parent and health physician in all departments, until the day before their child turns 18 (family/carer).

Value and Include

- **Making sure people have genuine choices about their health.**
    - Talk to me NOT my carer.
    - Brushing teeth is challenging and getting the right dentist that understands is a huge issue.
- **More recognition of, and quicker support for, mental health issues, although there is also some good practice.**
  "I am lonely and get fed up" (YPWLD)
  "Some doctors understand mental health needs. Some health centres are good at understanding how to support mental health needs."

"Being able to access early diagnosis of ADHD and/or Autism so support is in place sooner rather than later" (family/carer)

- **Friendly, consistent teams that encourage attendance at appointments.**
  - Specialist team at Badsley Moor Lane – good relationships with the staff mean I have less fear of blood tests, there is also prompt treatment and identification of health needs.
  - At primary health care centres appoint more specialist LD health care workers (or health advocates) to understand and work me, advocate for my needs to be met (see below) and support my family/carers.
    "All the people in the group felt they have access to their doctors, hospitals, specialists and medication where applicable" (practitioner)
- **Review/extend specialist community learning disability services** (practitioner)
  - Access to SEND school nurses for children who attend mainstream as well as special schools.
  - Relook at the criteria for accessing specialist community LD services, so that if I have not been known to services, or have a milder learning disability, I am not screened out for services. Work towards the best organisation/service that can meet my individual needs.
  - Teams seem under-resourced.
  - There is a division when it comes to the health of residents and hospital admissions between provision led by specialist learning disability nurses and those without (the statistic around mortality for me has not really changed despite Transforming Care.)

- **More training/education**
  - Make sure that schools and services know about, and promote, the annual health check.
  - Support me to recognise when I need to see a doctor/health care professional by teaching me terminology about me body and teaching me procedures for contacting doctors.
  - Provide more education for me and my family on increased health risks.
  - Give more support and information about what is involved in appointments, and how to make them.
  - Home visits would be helpful to explain these issues.

    - Train staff in all areas of health about responding to me/listening/giving me meaningful choices:
      "People with some quite complex health presentations are in supported living, or residential placement with staff who have very little training around...physical care needs...especially people with a learning disability who may not be able to verbally/or communicate information about their health." (practitioner)
      This can result in hospital admission when I might actually need a Care Act Assessment to access the support I need.
    - "More doctors need to understand how to support SEND young people and their mental health needs."
    - Health staff need to understand what a learning disability is for families from different backgrounds.
      "Doctors need to know what kinds of things you can and cannot do."
    - People need to understand how neurodivergence presents in females "All health professionals involved in diagnosing should take these differences into account." (family carer)
    - There could be more visibility of people with disabilities in the NHS.
    - There needs to be more training for health practitioners about any rare health condition I have, not just relying on my family/carer to provide information.
    - Give information and support via schools/colleges to me and my family/carers on healthy meals/eating, and offer cooking classes.
- **Greater accessibility/reasonable adjustments in health settings**
    - E.g. wheelchair access, wheelchair charge point, hoists, leg stirrups for a smear test at the doctors, ramps rather than steps (at the GP, pharmacy and dentist)
    - Provide access to transport for all appointments e.g. to the GP.
    - Have more women/girl only appointments.

Communicate

- **Listening to me <u>and</u> my family about what I need** (don't assume I don't know what you are talking about)
  "They think I can't think for myself."
  "Listen to the voice of the parent/carer when the child is non-verbal...my child needs full supervision as unaware of personal danger. LD care in hospital has only 3 part time staff to cover this, which has mostly not been enough."

    - Make support available for me when I am talking with doctors and nurses so that I feel understood.
    - People need to be trained to understand and ask the right questions of people who aren't able to communicate and advocate for themselves. This really matters.
- **Making it easier for me to book appointments for myself and offering me help to do this if I need it.**
  "Having to call the GP at 8am and having to wait for a long time once they have gone, that's it no appointment, call back 8am next day." (practitioner)
- **Giving more accessible information**
    - Make appointment letters and leaflets easier to read.
    - Provide more leaflets/guidance/talks so that me and my family know about increased health risks, what to expect and the importance of annual/regular health checks and attending screening appointments e.g. for diabetes/cancer, sexual health, mental health issues, toileting, body awareness.
    - Do a Health roadshow via schools.
      "...a lot of people don't engage with GPs, because they don't give accessible information."
    - Use pictures, but make them easier to understand (every word does not need a picture!)
    - Make sure all staff know how to organise a British Sign Language (BSL) interpreter as well as spoken language ones.
    - The LD team being more pro-active about the information provided.
    - Social workers/carers could offer more support so that I understand the processes better.
- **Options/different ways to order medication.**
- **Sending multiple accessible reminders about appointments, making clear what the appointment is for**
    - Offer regular check-ups that I don't have to ask, especially if I am on medication, so that I don't fall between cracks.
    - If I don't attend, instead of discharging, send a contact letter/call me.

Partnership

- **Considering the impact of the Annual Health Check** – there does not seem to be any quality assurance/they can be quite basic.
- **Helping to pay for health related things like life insurance.**

- **Closer partnership working between GPs and voluntary sector organisations.**
    - Familiar community-based organisations could offer spaces for healthcare e.g. community cafés "where I feel welcome" (PWLD)
    - Funding could be given to smaller groups who could hold health related workshops e.g. about cancer and long-term illness.
    - GPs could know more about, and make referrals to, voluntary sector organisations.

Community Inclusion

"We feel we have many good friends . Most places we go make us very welcome."

"Socialising"

"Finding a partner...having a relationship."

"That we continue to get a choice in our activities."

"Trips out are important."

But this can feel difficult:

"How can we fit in and be accepted in society without feeling different?"

"How do you provide support for people who say they don't need support?"

"I don't go out much to meet new people."

What is important to me?

Welcome and care

"The staff team are important to us."

"Seeing our friends and going to local groups is important to us, and seeing our family. I like to bus train to get to my location."

"My social worker does not care and my teachers are not nice to me" (YPLD)

"People are not nice to you or help you if they think you have a disability" (PWLD)

- **My experience and worry.**

"Places can be overwhelming, very noisy and crowded.

My mum always takes me to where I want to go.

We usually just game with each other or go to each other's houses.

We text and message.

I think I get looked at when I go to shops.

People don't always understand why I might behave the way I do and say something unkind to me or my parents.

I like going on trains and when people are sat in the disabled seats I will tell them they can't sit there - I have a right to them they don't.

Some cinemas have quieter times and it is good to go then.

At Alton Towers I can get a fast track ticket

Sometimes I can take someone with me for free.

I sometimes think it is just easier to stay at home by myself" (PWLD/autism)

"Sometimes people don't understand the way I speak and I get upset. But I do my best to communicate in different ways" (PWLD)

- **Belonging to a friendly, welcoming and caring community where you are valued, that also feels safe.**
  "Having a place to feel welcomed is massively important as the constant judgement can be too much at times, feeling valued and good communication is always a plus. I'm currently not aware of any environments like this." (Family/carer)
  "Rotherham has some wonderful places to visit and relax. I always feel welcomed." (Practitioner)
    - We need more LD/autism friendly environments.
    - There are examples of inclusive social opportunities that are valued e.g. REACH "making me feel safe, and happy;" Gateway Club "trust in staff to dance" "make friendships;" Burlington Bash; Tenacre (Voyagecare) "respite" (family carer); Speakup (practitioner), Unity Centre training centre /crafts "always make us feel welcome and friendly" (PWLD)
      "Toby carvery is brilliant always make you welcome" (PWLD)
      "Gateway pub managed by Mencap...Buzz bingo theme nights make you welcome." (PWLD)
    - Also support family carers to feel more confident because they are so busy caring they find it hard to ask for help. RPCF is valued by families.

  - More inclusive environments would help everybody feel welcome.
  - I want to be able to go to socialise at activities with my friends.
  - But I don't to feel treated like a toddler (PWLD/autism)
  - Some criteria to access groups can make them feel unwelcoming, as though they don't want me to work with them.
- **Recognising and rewarding amazing personal achievements**

Value and Include

- **There are some good specialist and universal organisations providing supportive environments that motivate me to go out and meet people.**
  - e.g. Speakup (practitioner)
  - "Guiding VOICES gets you out of the house" (PWLD)
  - "Ice Hockey crowd welcome you" (PWLD)
  - Gateway "There is someone there I don't like and sometimes the staff help me manage."
  - Libraries, some GP surgeries, My Place
- **Feeling part of a community is important but it is easy to feel excluded.** "We get left behind all the time" (PWLD)
  "Being made to feel like part of the community and being able to contribute to the community" [is important] (PWLD)
  - I do not always get the support I may need to access universal services unless my family/carer can provide it.
- **More focus on life skills to support independence** "People with special needs need better life skills. This will not only help them to integrate but will also show the people they come into contact with that they have something to offer." (PWLDs)
- **Being able to travel to more places; better transport is needed.**
  - Independent travel is empowering but there are a lot of barriers.
  - Public transport is "hit and miss" (PWLD) always late, the tram seems a lot better and on time.
  - It is great when a person can get somewhere as independently as possible e.g. community bus. It is important that where people go is where they want to go, and their views are respected. Restrictions on buses to some Rotherham villages make this difficult.

  "Some of our people are now unable to attend sessions due to transport cuts." (practitioner)

- **More training and awareness raising so that people are more supportive, including staff.**

"I sometime feel I don't have the same opportunities as normal people because I might need more help and struggle to do things on my own. People sometimes get mad when I am out places because I do things a lot slower." (PWLD)

  - More organisations, businesses and people in Health need to understand LD/neurodiversity e.g. in cinemas providing noise cancelling headphones that enable me to listen solely to the cinema and not everyone else speaking especially if I am hypersensitive to noise.
  - "Some carers don't like to talk about sex." (PWLD)

- **More diverse provision**
  - Affordable, more differentiated local clubs/events/activities (family/carer/PWLD).
  - More opportunities for BSL activities.
  - More places to go and more activities available for YP, older YP and adults with LD (PWLD/autism).
  - Holiday provision.
  - Being able to do groups e.g. scouts.
  - Groups with different age groups – where older ones support you (YPWLDs).
  - More to support men.
  - More to support people who have been in prison.
  - Different kinds of activities/opportunities to learn.
    - E.g. cooking
    - shopping online
    - shopping
- **Being able to access groups that connect you with people you relate to and help you make friends.**
  - Guiding Voices – having people I relate to (YPWLD).
    "I feel like there should be more support to get to places and meet people with the same disabilities as me." (PWLD)
  - Having somewhere to chat, like a café, to meet other people with autism (PWLD/autism).
  - "Social Eyes" is good (practitioner).
  - "Our people all said they love coming to Dexx on Mondays and/or Tuesdays and have made a friendship group, we do lots of activities and trips together, and we all enjoy this." (practitioner)

  - There are other great support groups (around Wath upon Dearne) like Community Connect, Gateway and the Burlington Club.
  - "People living in central Rotherham felt there was not as much available to them. They were unaware of many groups where they could meet other people and feel valued and welcomed." (practitioner)
  - Some people mention that Rotherham North does not provide as many groups for CYP with SEND
- **Having more flexibility, accessibility and reasonable adjustments in specialist and community areas**
  - My needs might change so it can be hard to pre-book.
  - "Some places make me feel overwhelmed, such as really busy places like shopping centres." (PWLD)
  - Automate bus pass renewal.
    "My sons bus pass has been a lifeline for him. Without it he will not be able to go anywhere as he's not capable of saving enough money to pay for bus fares and has only universal credit for his income. Automating the renewal process for bus passes would be super helpful and save a lot of hassle." (family/carer)
  - If I have a mild learning disability but need support socially I can fall through a gap in services.
  - We like it in places that are quieter in my area as it can be rough.
  - In parks it would be good to have a neuro-friendly dedicated spot in that is sound proof (e.g. a den).
  - Put some 'Adult gyms' in parks and the town centre.
  - Wheelchair use can make it hard to access some groups.
    - It would be good to have accessible pavements - dipped curbs - the dipped curbs don't always match up on the opposite side of the road which results in being on the road.
    - And wheelchair accessible buses, with more space.
  - More changing places are needed.
  - More support and help should be available when I need it.
  - We need more accessible parks and playgrounds for children with mobility issues (family carer).
- **Make being safe in the community is a priority.**
  - Some people have experienced abuse in provision they/their families thought was safe, which has understandably impacted on trust.

> "Some members feel vulnerable being on their own as they may get picked on by others; we need more cameras that are linked to Rotherham town centre, more police and community officers are needed especially at night." (practitioner)

- **Having more support for carers**
  Empower them, and recognise the skills they bring.

Communicate

- **Information I can understand.**
  - More information should be available and made easy to read on what's happening in my community.
  - There needs to be better communication about types of provision and welcoming spaces; more easy read information and forms instead of long documents to read about what support is available and how to access it.
  - An accessible 'one stop shop.'
    "one main central place that people with additional and learning needs can access to get the help and support needed so they do not have to travel to different areas for different services, they can find it all in one main place." (family/carer)
  - Receiving direct payments is a major obstacle, many BAMER families are unable to navigate the SCA (Social Care Assessment) service.
  - Difficulty understanding bus and train timetables can make independent travel hard. There should be accessible versions and easy ways to know if there has been a change.
  - Information about activities could be translated into local community languages/presented on video.
  - Do not rely on verbal information – use a range of ways of communicating with me e.g. writing something down if it needs to be remembered.
- **More people should be helped to have a voice** (YPWLDs)
  - People should speak to me not my carer (also see Health).
    "Apart from the parent carers forum I have no voice and neither does my child."
- **I only want to tell my story once** because of the trauma it creates (family carer).
- **There is a need for more transparency from services.**
- **Awareness raising – change the culture.**

    - It would be great to have a campaign in the local community to make local people/groups/shops less afraid of me.

Partnership

- **Working WITH us** (not to or for)
    - E.g. when a provider listens to family/person offer individual adjustments so that they feel welcomed (such as installing wi-fi).
    - Stop calling marginalised groups hard to reach; work harder to tackle the racism. Bring people together from different backgrounds. This would be a great idea because this does not happen very often – e.g. project around Wentworth Woodhouse (practitioner) – build a more integrated, cohesive town.
    - Give funding to smaller community groups who might provide a more bespoke service to support me in my own community, so that I can feel safe to access the activities.

What else is important to me?

The Learning Disability Strategy engagement process

- **Turning it into a longer term strategy for PWLDs**, reflecting the complexity of the population and incorporating our different needs.
    - I want to know more about how many PWLD there are in Rotherham.
- **Better quality assurance that takes account of what I say**
    - E.g. CQC (Care Quality Commission) to have more involvement with the care companies that are available across the borough.

"I'm finding that the care companies are not meeting the basic needs of the clients and their voices are not heard when complaining." (practitioner)

- **These questions (the survey) are hard, even with help.**
  "As a person with dyslexia and autism, I found this form impossible to fill out. Need to ask simple clear questions, not just what's important written in lots of different ways." (PWLD/autism)
- **Include <u>all</u> relevant community organisations** when working on this strategy (e.g. SEND youth groups, BME SEND group).
  "Please work with organisations like ours who are at the forefront of grassroots and have an excellent understanding of the communities they serve." (practitioner)
- **More time is needed** to gather voice from the people this strategy concerns, especially from small groups; more work and time is needed to

approach disabled children and adults from BAME communities, vital information is being missed.