

Consultation period: 4th February to – 23 April 2019

Leicester City Joint Health and Social Care Learning Disability Strategy 2020/2023

‘The Big Plan’

Full Consultation Report

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1. Purpose of the consultation

Leicester City council and Leicester City Clinical Commissioning groups carried out a consultation during 2019 on a proposed joint health and social care learning disability strategy. The consultation ran from 4th of February to 29th April 2019.

The consultation was carried out to ensure the Leicester City joint health and social care learning disability strategy appropriately identified the core priorities and actions to improve access to health and social care services for people who have a learning disability and people who have autism and a learning disability.

The strategy was developed in co-production with the members of the learning disability partnership board, including members of the self-advocacy groups 'We Think' run by Mosaic, the 'Talk and Listen' run by the Leicestershire Partnership Trust, and staff and users of 'The Carers Centre'.

The consultation exercise had 3 main aims:

1. To ensure that the right priorities have been identified;
2. To establish if there are any areas that were not identified.
3. To seek wider opinions and ideas on how to achieve the aims detailed in the draft.

The draft strategy detailed several core priorities and necessary actions in the following areas:

- Social Care
- Housing and Accommodation
- Work, College and Money
- Equal health care
- Health lifestyles
- Transitions into adult hood
- Support for carers

2. Consultation methods

2.1 Survey

A survey was carried out using the council's Consultation Hub. The questionnaire was also made available in printed form upon request or through printing a PDF version. A postal option was available, and people were invited to contact the consultation team by telephone or email to request postal surveys and pre-paid envelopes.

The draft strategy and survey questions were also made available in easy read (all consultation materials are available at appendix A)

2.2 Meetings

Nine open public consultation meetings were arranged. These were located within each area of the city to ensure people in different wards would have the opportunity to attend a meeting if they wished.

A letter informing people of the open consultation meetings was sent out to over 750 people who have a learning disability, and / or their family carers or paid support provider.

The open meetings were also advertised across Leicester City councils LD services contracted providers.

A total of fifteen meetings were arranged across east, west, south and central areas of Leicester City:

- Nine open public consultation meetings
- Two meetings for providers and health and social care professionals
- Four meetings with service user groups

The sessions were jointly hosted by Leicester City Council Strategic Commissioning team and east Leicestershire clinical commission team.

A power point presentation was developed to aid the meetings and support discussions, the slides delivered at the open consultation meetings included:

- An introduction to the strategy,
- Why a strategy is needed
- Stakeholders involved in co-producing the strategy.
- The core priorities for each areas
 - Social Care
 - Housing and Accommodation
 - Work, College and Money
 - Equal health care
 - Health lifestyles
 - Transitions into adult hood
 - Support for carers
- Feedback from attendees
 - Did attendees agree with proposed priorities
 - Were there any areas that had been missed.
 - What ideas did people have to achieve the objectives within the strategy
- Next steps and how to complete individual survey responses

However, the structure of the meetings also allowed for conversations to focus on specific issues and areas that were of specific interest to the group of people attending.

Where agreed by attendees the sessions were recorded and key notes were taken from these recordings.

2.3. Letters

We received feedback in the form of a letter from one person who was a family carer of a person with a learning disability.

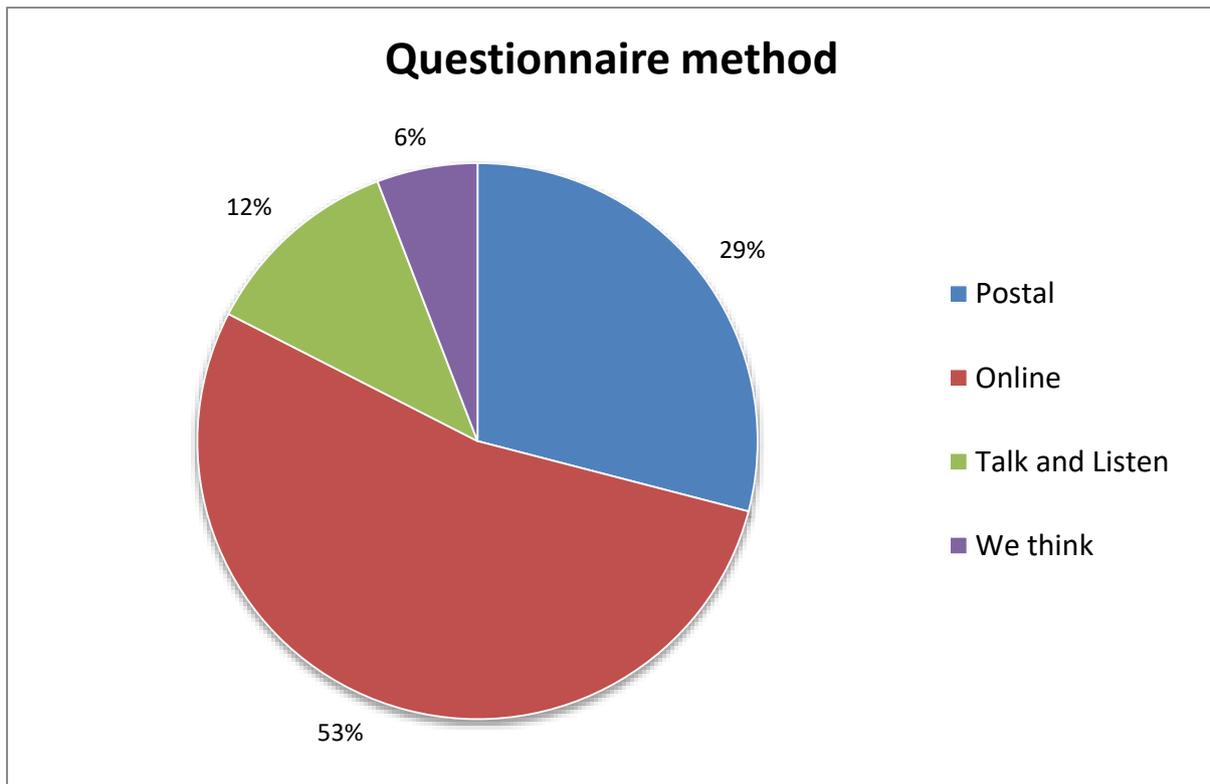
2.4. Interviews

There was an extensive interview with health watch Leicester and Leicestershire to establish an independent view point on the draft strategy from a statutory assurance board. The interview was with a board member of health watch Leicester and Leicestershire who attends as a member of the learning disability partnership board.

3. Consultation findings

In total, 86 individuals participated in the survey. One questionnaire returned represented the views of five individuals. Although all those respondents gave the same answer to the yes/no questions and are included in the survey analysis, the demographic questions were completed only once, so it was not possible to count those respondents individually in the demographic data. However, this would not affect the overall outcome of the survey.

Responses were received via postal return, online, at meetings of 'Talk and Listen and 'We Think'

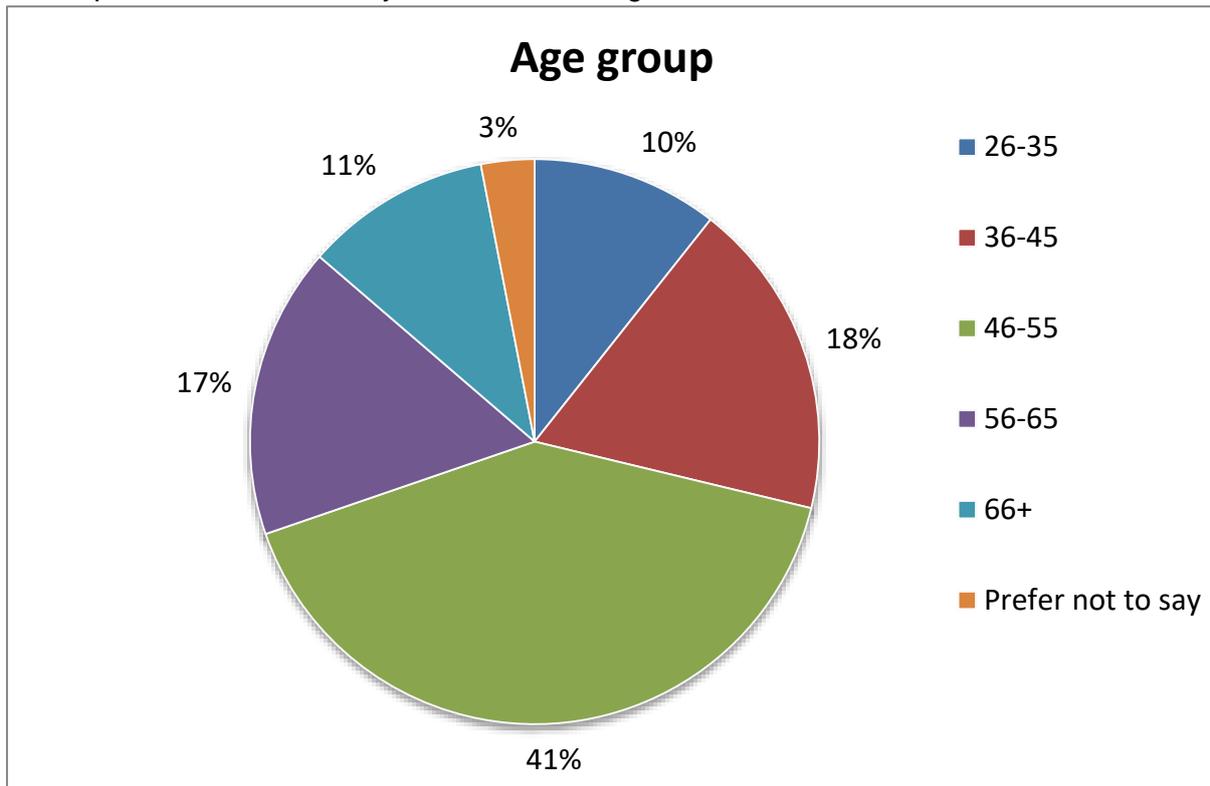


3.1 Profile of survey respondents

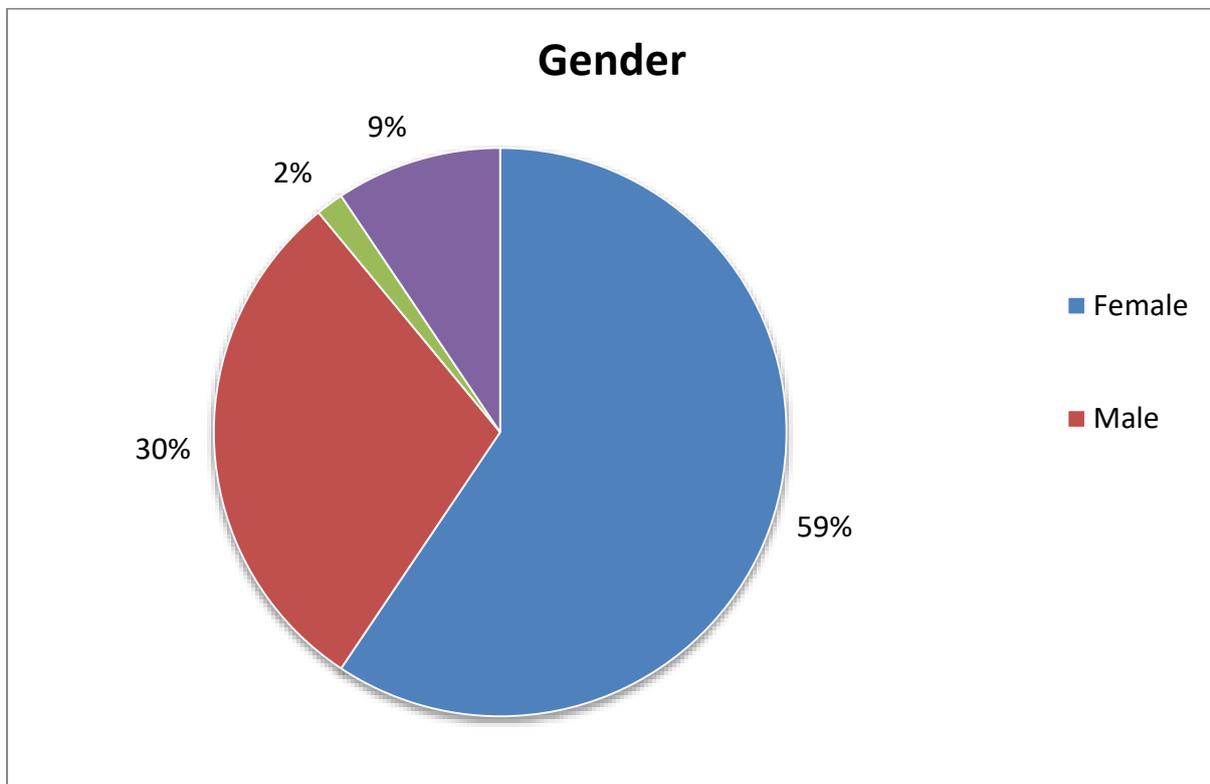
The main demographic characteristics of respondents were:

3.1.1 Age Group

No respondents to this survey were under the age of 26.



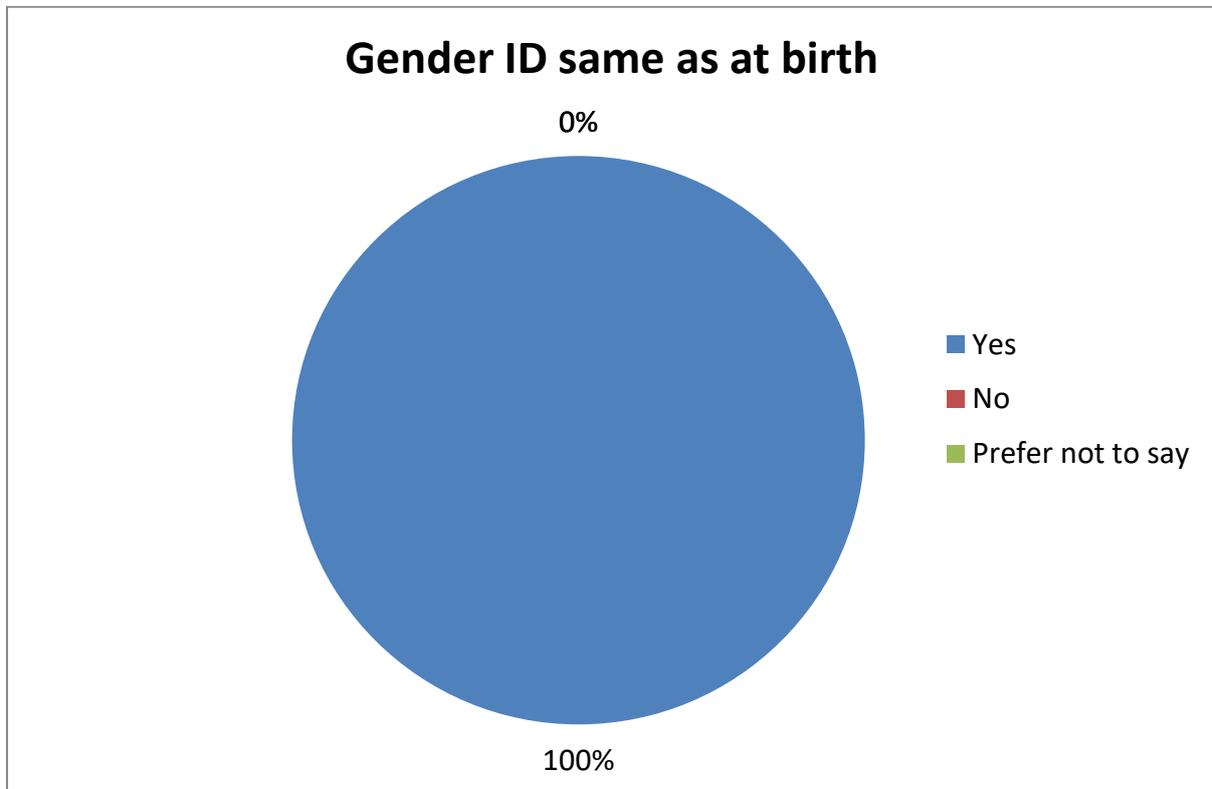
3.1.2 Gender



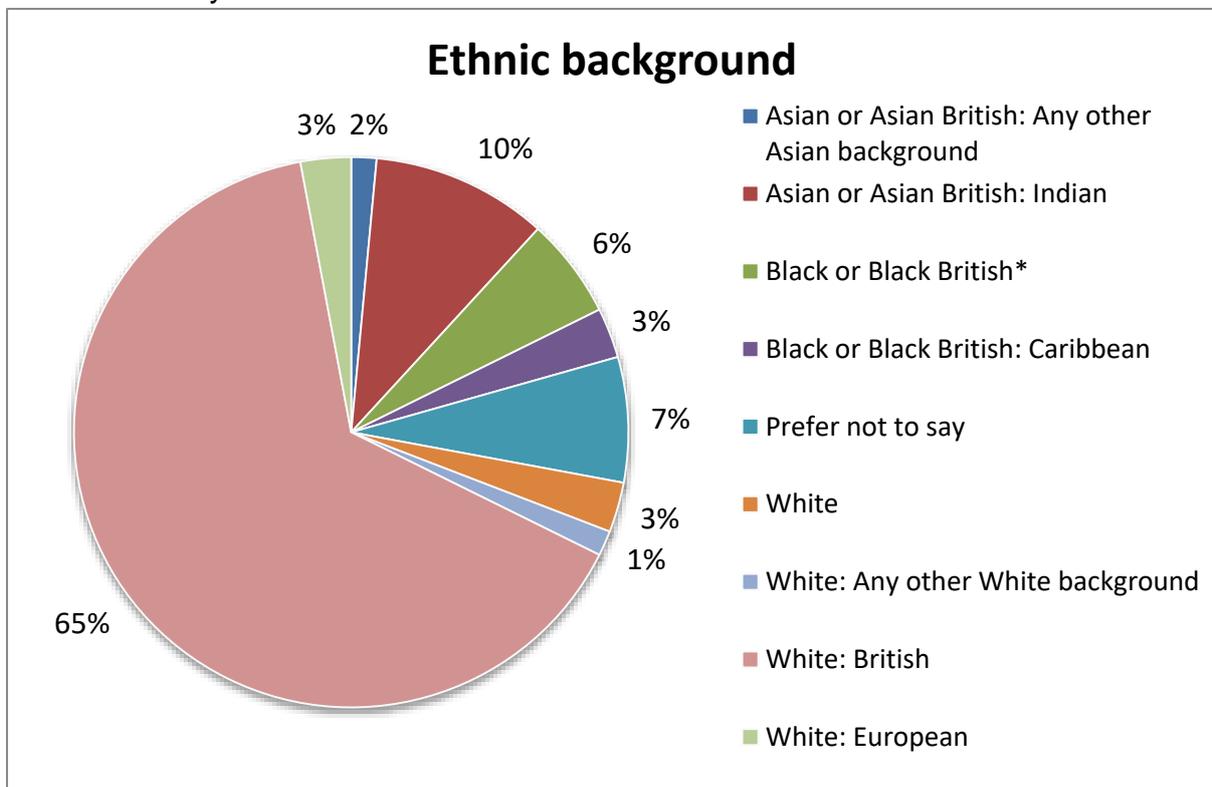
One respondent who stated 'other' gender, did not define this, but stated that they preferred to use their own term.

3.1.3 Gender identity changes

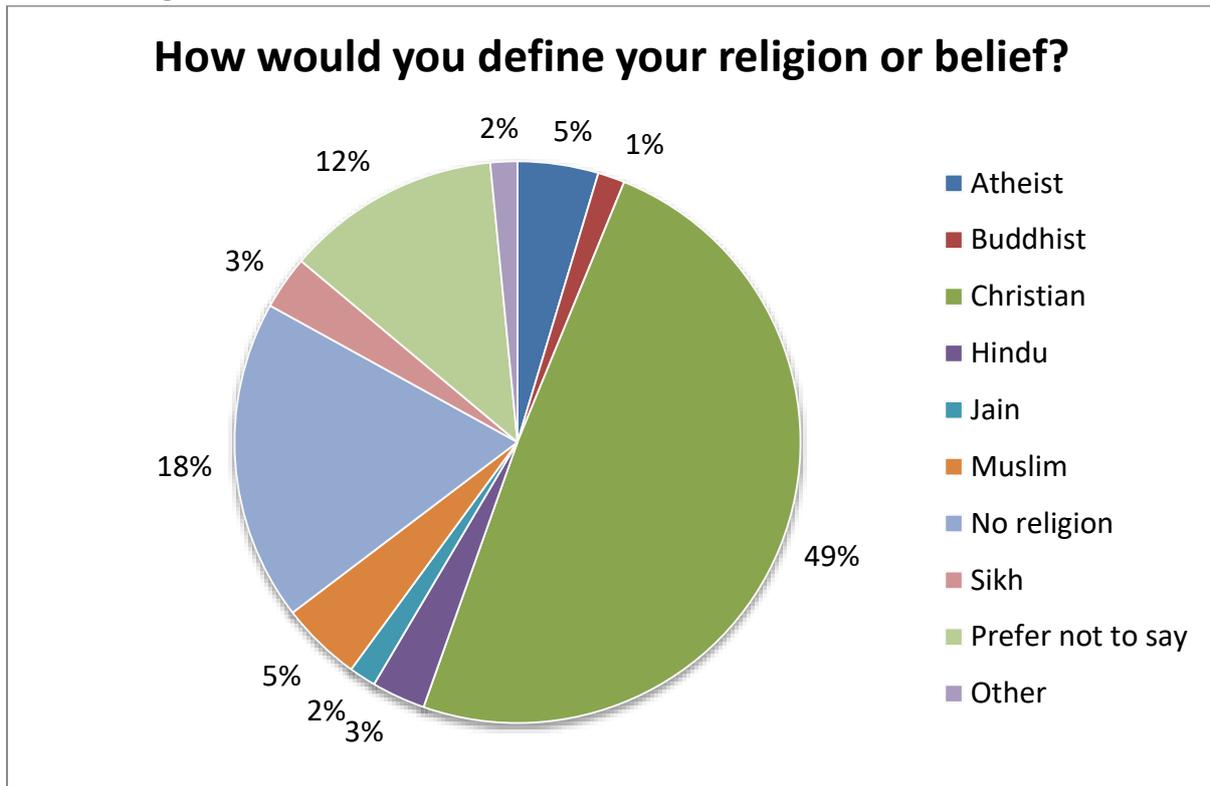
All respondents who answered this question stated their gender identity had not changed since birth.



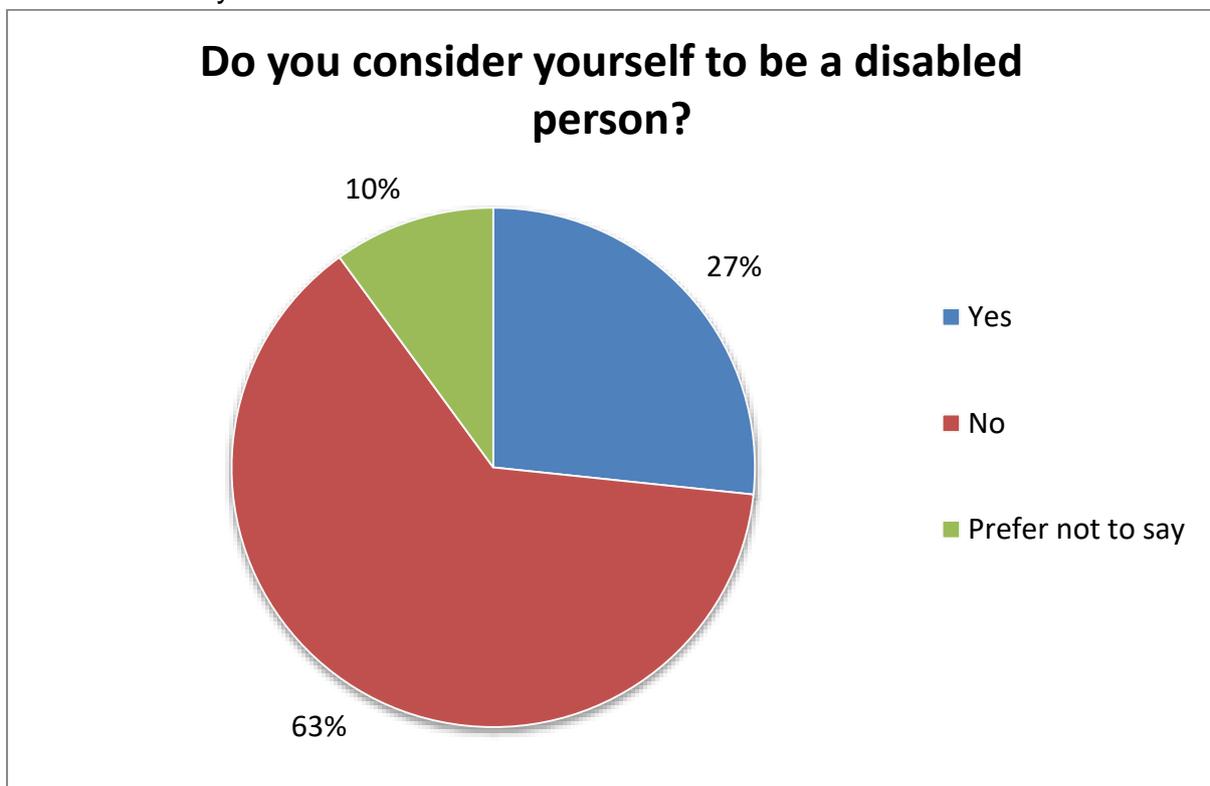
3.1.4 Ethnicity



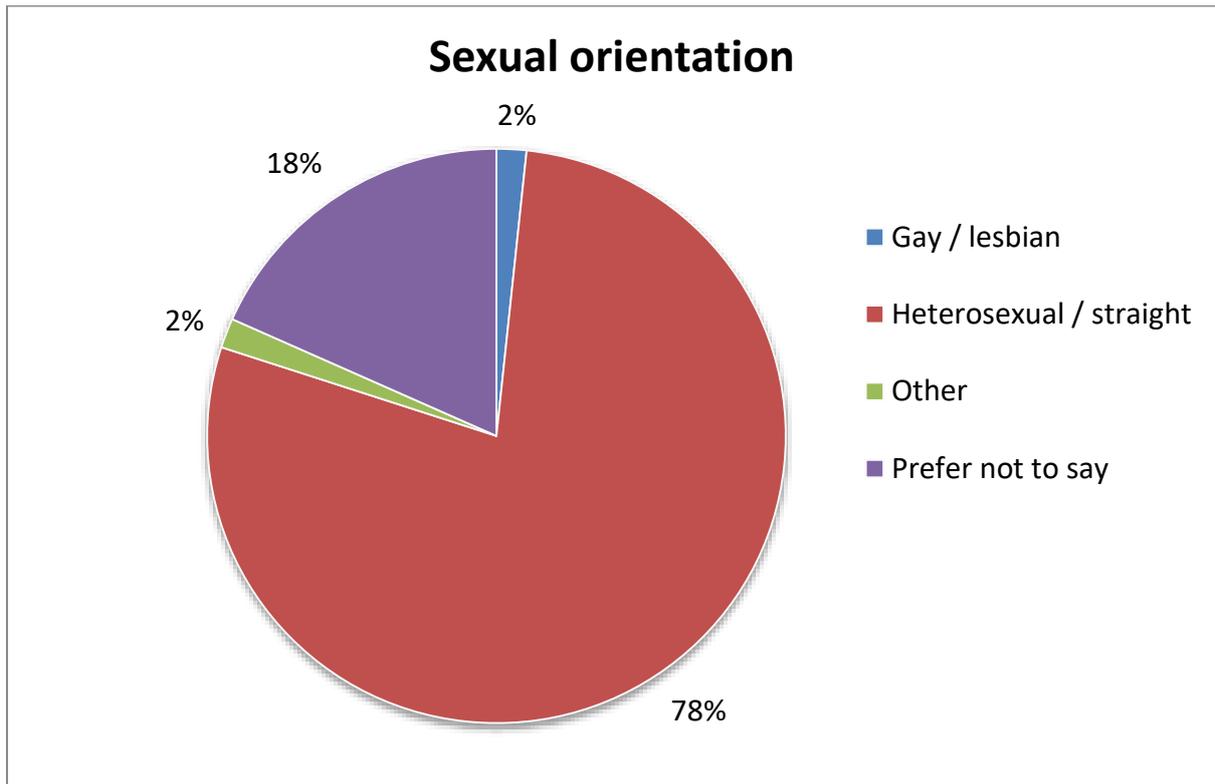
3.1.5 Religion



3.1.6 Disability

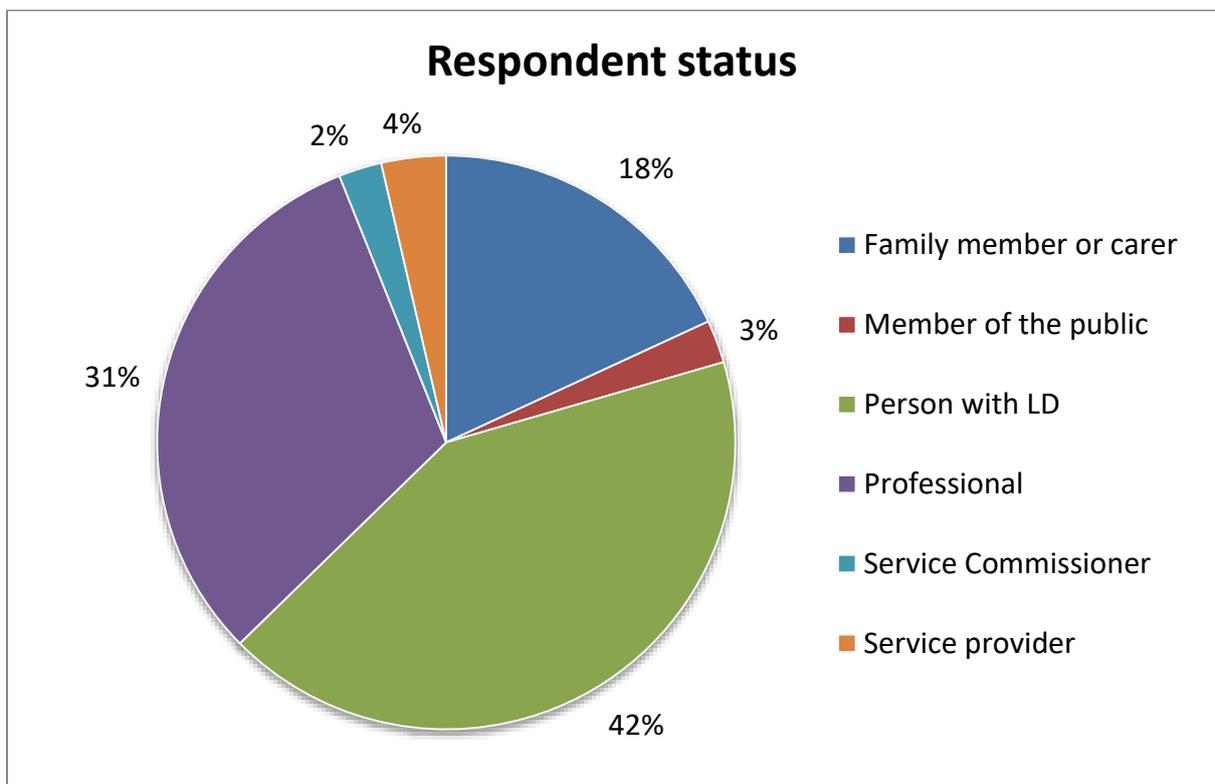


3.1.7 Sexual orientation



3.1.8 Respondent role

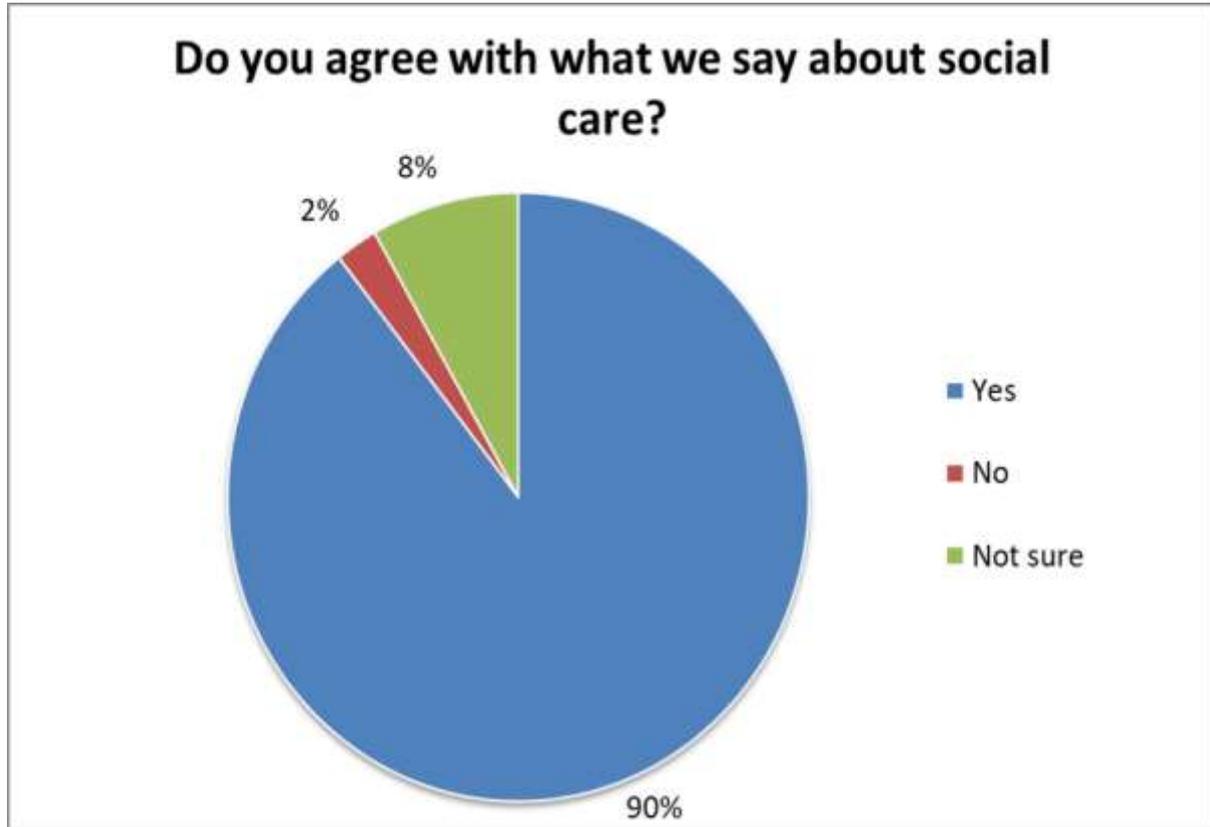
The survey also asked respondents to say in what role they were completing the questionnaire.



3.2 Survey findings

Respondents were asked whether they agreed with what we said on a number of topics. Generally, responses were positive, with between 89% and 91% of respondents agreeing. For each topic, respondents were invited to give any comments and these are presented within each topic subsection below.

3.2.1 Social Care



Comments on social care

People with a learning disability

Comments received from people with a learning disability (service users) highlighted accessibility, assessments, changes to care and the need for assistance;

Accessibility of information about themselves and about the service was important to service users;

"It is important that I understand what is written about me."

"When are the easy read assessment forms going to be used/ have they have been developed yet?"

"Some people need more help than others."

"I think that they (services) should still be more learning disabilities friendly."

“Also, phrasing and words should not be made up of jargon. Using more easily-read terms, enables the client to understand.”

“...talk in a way I can understand.”

“Easy read (forms etc).”

“Sometimes the writing in letter could bigger to help me to read it.”

Legal language was specifically mentioned, suggesting that where such language may a requirement, a clear explanation of what it means would be useful for the reader;

“Emphasis on legal terms and associated terminology, to cover the agency or provider of the care, is not appropriate.”

Meeting needs and changes to care, sometimes at short notice or without the agreement of the recipient, were a cause for concern;

“Cancelling care happens to me without my permission, more notice should be given. I am often without support.”

“I have issues with care/support being cancelled without...being consulted”

“Carers used to sit next to me and not talk to me.”

“...how are you going to ensure support doesn't get cancelled without permission?”

“Changes to care/support in any way, without consultation, often cause anxiety and distress. Some clients may say little, and try to cope. So, great care needs to be taken by those providing the care.”

Assessments and updates to them were a concern for one respondent;

“Assessments were written and made in the past, but rarely updated and never implemented...”

“A person's lifestyle (is) mostly ignored and never taken seriously. Overall their needs and support are not to their satisfaction.”

“Care should be person centred - but I sometimes I feel I need more help than I receive.”

Family members/carers

Comments from carers on social care, similarly to those from service users, included concerns around accessibility and clear information. Carers also expressed concern around the needs of service users not being fully met, particularly in education.

Accessibility concerns focused on clarity of information for all service users, from affordability and full information not being provided early on, to service design;

“Please remember some people with learning disability are unable to read and write.”

“Affordable to all and without any form of means testing.”

“No thought is being given to the accessibility needs of people with learning disability, mental health illness and their carers; whether that be the physical building or the appointment booking systems and cross department communication”. (Reference to accessibility of the design of the extension of Leicester Royal Infirmary and the General hospital.)

“...detail(ed) list or website (of) accessible and up to date services, city and county-wide if possible.”

However, some carers felt that ‘one size does not fit all’;

“...having an easy to read document (for highly intelligent people with autism) is an insult to their intelligence and can appear demeaning. Documentation must be person-centred to their needs and not to assume pictures help in any way.”

Education and choices around it were mentioned in detail;

“...great primary and secondary school education. Afterwards, there is nothing appropriate for (the service user’s) skills. ICT, the only choice, is a time-wasting course at Leicester College or me home educating, enrolling him on adult education classes and attending as his carer.”

“My son could be a taxpayer at some point, if he could access a suitable course with vocational skills. Currently I don’t see that happening.”

“Choice is a great aspiration but the reality is that appropriate educational and recreational provision does not exist. Therefore there is no choice.”

“Working with education providers is a great idea; however my experience of Further Education for SEN students at Leicester College is that (it is) more in line with childcare and not education.”

There was also some frustration around ring-fenced funding payments to recipients;

“Parents want some organised regular activities for their children /adults using their Direct Payment for respite or social care provision. I would happily offer Leicester college my son’s direct payment for the social care but it is not education.”

Efficacy of partnership working between service providers and commissioners was challenged;

“Working with the NHS, CCGs and Trusts is very sensible however they are not interested in participating. How is Leicester City Council going to show them the benefits of collaborative working and public engagement?”

“Surely (Leicester City Council) can make demands about standards (at Leicester College), human resources (teachers /lecturers /teaching assistant/admin),

accreditation (AIM Awards, ECDL, Basic Food Hygiene cert), monitoring of progress, competence, disability discrimination and reasonable adjustments.”

One carer felt that;

“Social care workers and education providers need to be aware of the side effects of medicines taken by people with learning disabilities, report suspected side effects and adapt the support offered to accommodate those reactions.”

Service providers, professionals and commissioners

Comments from this group covered accessibility for people with learning disabilities, partnership working and communication, workloads, processes and capacity to deliver what service users needed.

Some respondents were concerned about sustainability in delivering services to meet needs of users;

“Making time to complete assessments & support plans means that those at the top should recognise the pressure on their employees and as such provide the appropriate number of staff with the correct training & skills to carry out their job. For instance less process-driven and more person-centred.”

“(Social care) along with NHS services are severely under financed and face cut backs continually; experienced staff can no longer prop up an ailing area of care-providing, some of the most vulnerable requiring better and more funded places in the community, not less.”

“More money is needed in special schools to get better resources in order to help children reach their full potential. More time is needed to ensure that all needs are met in the best way for the individual.”

“How will this capacity be created?”

“Time is a key factor when delivering service often our own process delay(s) commissioning of service.”

“I'm not aware of being able to (make documents accessible); I have never been trained on how to produce easy read versions of documents. Whilst I agree in theory, there needs to be support to put these things into action.”

Accessibility for service users was raised, including involving people with a learning disability in creating materials;

“Health also make easy read information and would be happy to collaborate. Could people with learning disability be involved in checking the quality of the accessible information?”

“Be consistent with our service delivery. Be clear when acting as appointees to manage peoples finances. Ensure clear and understandable communication - work

with communication passports. Staff to be knowledgeable about people with Learning Disabilities.”

“Some of the things in the document don't seem achievable - such as providing easy read versions of assessments.”

“Easy read - feel that someone else would need to translate the assessment to easy read. Some people's needs are complex and people need the complex information e.g. potential providers.”

Communication and effective partnerships were felt to be lacking;

“As a representative of the 3rd sector I find it increasingly frustrating at the perceived lack of communication between the various supposed partners. County don't talk to the City, neither talk properly to the NHS and anyway, the Partnership Trust doesn't talk to the Hospitals Trust and no one talks to the 3rd sector (which) could well solve many of the problems. On the other hand no one in the 3rd sector talk to each other anyway!”

“Will it be implemented? Will everyone have access to it and not be fobbed off or passed on to the next agency”

“It would be good if social workers and individuals from the Council had an understanding of providers, with regard to their limits what they can and can't do and how to work together.”

“The concept of a one-stop shop for information is excellent but the county are also doing this so where does a carer or parent turn to for peer reviewed impartial advice?”

Some respondents felt that detail was vague, making it difficult to implement;

“What will 'meaningful choice' and 'making it real' look like when services are under pressure to save money? Social workers need to have specialist skills and understanding in working with people with a learning disability.”

“How will they do this?”

“Meaningful choice” - this is rather vague & not clear how this can be achieved. A major factor in this is funding & we have to work with what is actually realistically available. This bit sounds rather vague to me.”

Other respondents felt that parents and carers should be encouraged and supported very early to help people with LD to engage with services and their needs better captured in assessment;

“Parents/carers of children and young people need to be positively encouraged to engage with social care professionals at an early point in their child's life to allow time for trusting relationships, knowledge and understanding to develop.”

“On the whole I think this is good. Emotional needs crucial - should be incorporated more explicitly into the assessment itself. Not currently referred to explicitly within the actual assessment & I think emotional needs can be therefore sidelined.”

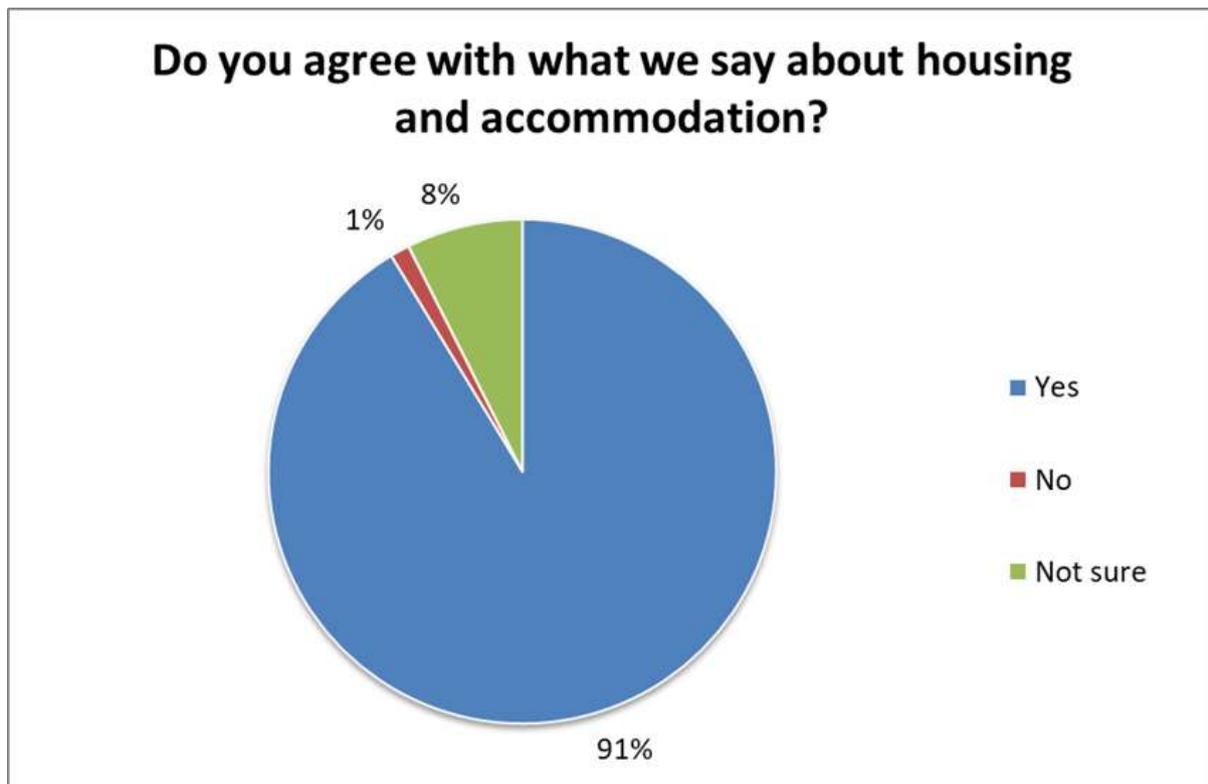
Members of the public

Comments from members of the public demonstrated their views that it was unclear what was possible;

“Very ambiguous statements overall.”

“Offering “more choice of what support people want” - this does not specify the conditions of the choice, whether this choice is appropriate or whether financially possible.”

3.2.2 Housing and accommodation



Comments on housing and accommodation

People with a learning disability

Some people with LD felt that organisations managing housing did not fully appreciate needs or have full knowledge of stock available, and that specialist housing officers should be employed;

“Many (housing associations) now have no housing officers, or staff that know the housing stock, let alone the area they are in. For people with disabilities etc., this makes life more problematic; they have nowhere to turn to get more focussed help. Even support workers struggle to speak to council/H.A staff about the special needs a client may have. The response is usually “sorry, we are unable to discriminate.””

“If this consultation is going to result in active changes, housing officers for people with disabilities is essential and a vital part of providing a better service. Without housing officers finding appropriate housing, it is badly flawed.”

“I feel that there is shortage of available homes.”

“It is not good if people don’t get choice.”

One respondent said that potential tenants did not always agree with how available stock was described;

“A local housing association advertised a vacant property as being suitable for a family. This property was a small 2 bed bungalow, among other small bungalows, suitable for the over 55 year old age group. I had to contact the housing association concerned, and get them to understand how wrong their advert/availability was.”

“...it is important that houses are clean.”

In choosing accommodation, people felt there was lack of choice and expressed what they felt was important in choosing.

“(There) should be more accommodation available for people with LD to give choice often you have to take what available as not enough.”

Respondents felt it was important to be close to home;

“I think it is vital and should be first priority for adults with disability to live close by to their family.”

Others prioritised feelings about home;

“...it is important that you are happy where you are living.”

Costs were important;

“Council Tax issue, shouldn’t have to pay.”

Service users felt that staff were good, but more support was needed in attaining and adapting housing;

“...the process should be easier from bidding to signing the tenancy.”

“Not always possible to make that happen as choices are not available very hard for carers to support you need to bid. They should manage training better, some people are placed in unsuitable placements and have no choice move (their) life but make sure they understand, if they able to make the choice let them.”

“Staff really good.”

“...need support to bid.”

“I would like more support in getting my house how I would like it. I would like a walk in bath rather than bath chair - this would make easier for me and my carers”

Staff support was a concern;

“More training on challenging behaviour.”

“...wanted staff in building at all times - only staff around are in my hours of support.”

Family members/carers

Families were concerned about continuity for the person they care for;

“Is there anything in the plan for person with learning disability to stay in their own house after their parents have died?”

Choice and suitability were concerns too;

“There is almost nothing for those at the profound and multiple disability range.”

“Choice - shared lives respite care offered 'joint accommodation.’”

Living conditions and safety were a concern for family members and carers;

“I have seen photos from an adult with LD of the mouldy walls in her rented flat. There is no way she has the ability to apply for housing, benefits etc. and so someone has assessed that property as being fit for human habitation.”

“People with LD are often placed in the same building /block of flats as other people with LD. This can work but I hear of bullying led by a person with LD against another. The victim has no one to turn to.”

“I have seen photos from an adult with LD of the mouldy walls in her rented flat. There is no way she has the ability to apply for housing, benefits etc. and so someone has assessed that property as being fit for human habitation.”

“Some residents with an emergency cord or intercom don't have their call answered and often are told to ring someone else e.g. 999 when it is not really a 999 emergency situation.”

“Council need to check that adults with LD are visited in their own home and an assessment done on the safety of the property and others who also reside or visit. There are safeguarding horror stories of the way families lock away their disabled relatives and use the direct payment on themselves.”

One respondent felt it was not realistic;

“It's all cloud cuckoo land, pretty well the same as the County and unfortunately likewise not worth the paper it was written because unless there (are) rapid changes

in government and general attitudes, less and less money and support will be available”

Service providers, professionals and commissioners

This group of respondents also identified lack of support

“It is very important to make (the) system more easy to understand and to give the right level of support...this requires enough appropriately trained and skilled staff.”

“A need for specialist support providers to be able to support complex clients and there needs.”

“We should ensure that all people with learning disabilities are catered for in whatever is required. People with learning disabilities should not be treated differently to other people, they are the same as you and me”

Comments on choice and availability in housing were also common in this group;

“We need move opportunities for people who are being given the choice to move into supported living the opportunity to try it first, either through having respite as part of the next step or just to try out before making that choice, if for example moving from residential out into support living or if moving out of the family home.”

“Choice can be costly, how is this going to happen?”

“More scheme accommodation is needed in a variety of areas to enable accommodation to be offered in different areas that clients would like to live.”

“That there needs to be a way of keeping more 'spaces' available for people who need accommodation in a hurry (and I know that isn't cost effective), but it the effect of moving people out of county can be devastating for them and their families.”

“Housing is a really big issue; more supported living accommodation is required for people with a Learning Disability, to ensure there is more choice available.”

“Providers often under pressure to fill voids, meaning that the process by which a person might normally have more choice gets compromised.”

“More realistic timescales and matching abilities needed, not just that there is a void so whoever comes first can be placed.”

“Whilst choice should always be paramount we have to be mindful as to what actually is out there as we shouldn't offer people things that simply aren't out there. Health have an unrealistic idea of what housing is available.”

Involving and listening to people with LD was important to respondents too;

“People need to be more involved than they already are. Housing needs to take better account of the views of service users.”

Property condition was another aspect picked up by this group;

“Housing providers often slow to respond to providers' requests to improve properties. Situations often have to hit a crisis point before action is taken.”

Support for people into housing and maintaining tenancy was questioned;

“The legalities of signing tenancy agreements and licence agreements needs to be explored as a lot of people with a learning disability have no understanding of what this legal document means that they are signing. Do they have the mental capacity to sign a legal document?”

“What about at risk of eviction with special needs - how are they supported into housing?”

“There are individuals who want to move but cannot because the support is not there to help them bid for properties, there are individuals who do have complex and challenging behaviour but are no suitable supported living placements so that they have to remain in unsuitable placements, more support and available suitable properties are needed.”

“There's not enough facilities within the communities for all to have easy access to.”

“(People with a learning disability) should not be forced to have to stay with parents and should have the chances of living their own life, even if from time to time someone pops in to ensure that everything is okay and also that when they need help they get it and if it requires data to be filled in then help is available for them.”

Support for families of people moving into housing was also a concern for this group;

“Support for family members who are struggling with letting go of their family member and are worried about supported living.”

However, respondents were optimistic about proposed outcomes;

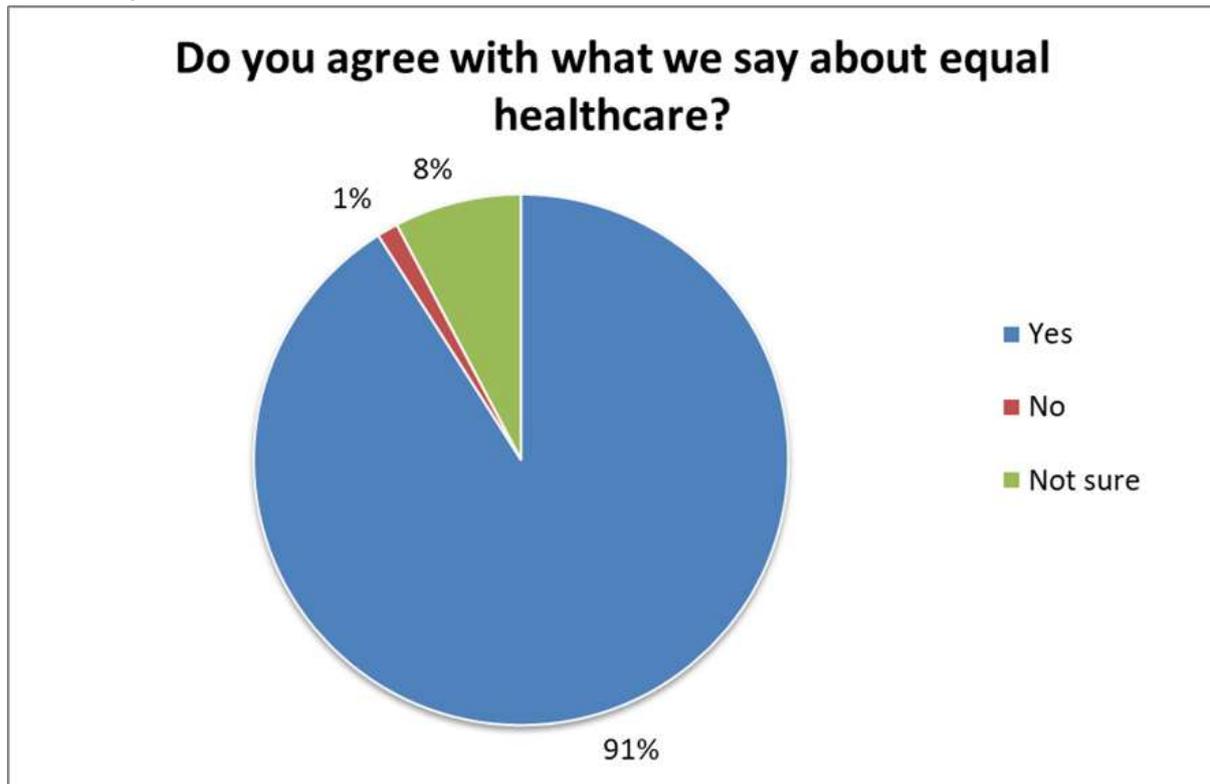
“It all sounds really positive. Expanding access to different forms of supported living would be really useful.”

“If the outcomes stated in the strategy around housing and accommodation can be achieved this would be fantastic!”

Members of the public

No comments were received from members of the public on this topic.

3.2.3 Equal healthcare



Comments on equal healthcare

People with a learning disability

Respondents from this group felt that healthcare still needed to be more accessible and staff better supported by training;

"I think doctors and nurses should have more timescale for appointments and prepared to see someone with special needs."

"All healthcare professionals should have training (in LD)."

"Doctors and nurses should all have training."

"I think this is good I used to have support for foot care but my doctor has said they can't do this now I hope the training will help this."

"There needs to be more doctor appointments as the doctor is often fully booked."

"I would prefer if all hospitals and doctors/surgeons (make) reasonable adjustments"

"If someone's second language is English, would there be a translator to explain things?"

"If (health care professionals) can only see the disability, they are in trouble. By the time they see patients they should have already had all the appropriate training, to enable them to help and assist the patient in the best way possible."

"I had to wait an extra day to be discharged from hospital because I needed LD nurse first – we need more acute liaison nurses."

Health checks were seen as positive, though there was an issue with take-up and lack of support;

"Health checks should be better but cannot force people to go all care providers should be more involved supporting people to go."

"Really important to have the health check each year and people get the support they need to go to these appointments and follow the health action plan they are given"

"My health check is thorough and she is nice, the doctor."

There was some scepticism about how achievable equal healthcare was;

"How can healthcare be equal? People with a learning disability do not receive the same health care as others."

"There are some very idealistic statements written."

"Many health care professionals are under so much pressure to see all the patients they must see, they have little time to go into the minutiae of each person's health needs."

"Signing a charter does improve services. It just means they have signed a charter, a piece of paper. Why not go for excellence in care services. Do away with charters, surveys and tick boxes."

One respondent was aware of their need to take care of their own health;

"I know I need to start swimming!"

Family members/carers

Accessibility and lack of understanding was also high on the list for this group;

"From experience taking daughter to the G.P., they don't really understand much about the person's health and would prescribe medications that don't really help the inner problems of their health. Many times it's (assumed to be) their behaviour, as a person with LD can't explain."

"Digital display boards in waiting rooms etc. are distressing for some patients with visual impairment and epilepsy. A separate room needs to be available for those with sensory needs."

"It is my experience that those who deal with very severely disabled people judge quality of life by the ability to walk and talk and they find it hard in the first instance to have a balanced judgement. All these little judgements and assumptions can lead to poor standards of care."

"More hoist changing facilities need to be available in NHS centres."

“Should training of all professionals include Autism awareness training as well as learning disability awareness?”

“The health checks are not thorough enough, e.g. it can be extremely difficult to get blood samples so it is just left, with obvious potential problems. Time with GP is never long enough to get full picture and our experiences in hospital are awful beyond belief. It seems that time is a large factor in all these things as well as attitudes and assumptions about any given person's quality of life.”

A suggestion to assist with this was offered;

“A card for those more independent people within learning disabilities, that they can use when they go to A&E.”

However, the support from health care professionals was acknowledged and valued;

“Health visitors' home visits should be compulsory for all new parents, especially those parents with SEN or other complex needs. This is essential for the safeguarding of the baby and the wellbeing of the parents. My health visitor was an essential part of recognising my son's additional needs and making suggestions to me about how to make my house as safe as possible as I was a single parent and had epilepsy.”

Health checks and uptake of them was also a concern for family members and carers;

“No one at special school or the GP told me that my son could have an annual learning disability wellbeing assessment. If no one publicises it then uptake will be low...all adults with LD should be on the LD register to ensure that they get LD nursing support if they attend hospital. The SEN school or GP should have mentioned this to me, they didn't.”

“The LD assessment at GP surgery is a perfect opportunity to view the patient in an holistic way, raise any safeguarding concerns and assess whether the medication prescribed could be contributing to the severity of symptoms, in particular mental health and epilepsy medication.”

“But join up so that social services, carers as well as the NHS have a report on it. Health Checks - Centralised. Ensured that they happen.”

One respondent pointed out that other family members' healthcare could affect the people they cared for and support was needed;

“I had an MRI scan recently, I had no carer to look after my son while I was in there, I came out of the scan early and my son had left the waiting room and gone for a walk round the hospital. I was very stressed out and woozy from the MRI. It would have been nice if I could have had someone at the hospital to keep an eye on my son while I was in my appointment.”

Another commented on staff concerns;

“Whistleblowers need adequate whistleblower protection.”

Service providers, professionals and commissioners

This group too recognised the need for effective training of staff;

“More than just e-learning is required. From personal experience health staff in particular do not recognise invisible disabilities such as autism.”

“Are staff trained to understand that people with LD are not always able to say what is wrong with them?”

“The LeDeR reports are helpful in informing the health team in their planning.

“The LD team in health offers training in making information accessible and would be happy to share our training with you / collaborate as appropriate.”

Health checks

“Healthcare for individuals with a learning disability has improved, due to campaigns and better awareness, but there are still individuals who will refuse a health check despite understanding the possible risk involved, any professional who works with or supports an individual with a learning disability should have learning disability awareness training.”

“Familiarity with service users ensures that staff do not miss vital signs.”

Support to attend appointments and manage outcomes from those was a concern;

“What about support for people who live in the community and only have small packages of support and require support to health appointments / annual health check or if bigger health issues are found, how does the person access more support to go through any bigger health problems, such as a cancer diagnosis?”

“(Equal healthcare) is something that should be factored in to support, ensuring all our individuals receive the same health care benefits as everyone else having a disability should not impact on this.”

“Constipation in people with a learning disability has been a contributory factor in a lot of deaths. Are people aware of this?”

Some felt that ‘old ground’ was being gone over;

“None of this is new and should be in place already. Services are really good at saying what should happen but there is never any detail how and also how individuals are held to account if it doesn’t. This is years-old national drivers that have failed to be implemented.”

“this has been something that has been talked about since Valuing people was published. It seems that more needs to be done in healthcare settings around access and that the views of people with learning disabilities are listened to.”

Seamless services were needed;

“Consider how to make the transition from children's to adult services much smoother for young people and their families.”

“Will Healthcare link with education to support especially children on EHC plans and input to them in a timely manner? Will education get information about children under health care professionals without having to badger for it, especially for children with EHC plans?”

One respondent felt that referral was best;

“Better signposting to existing resources.”

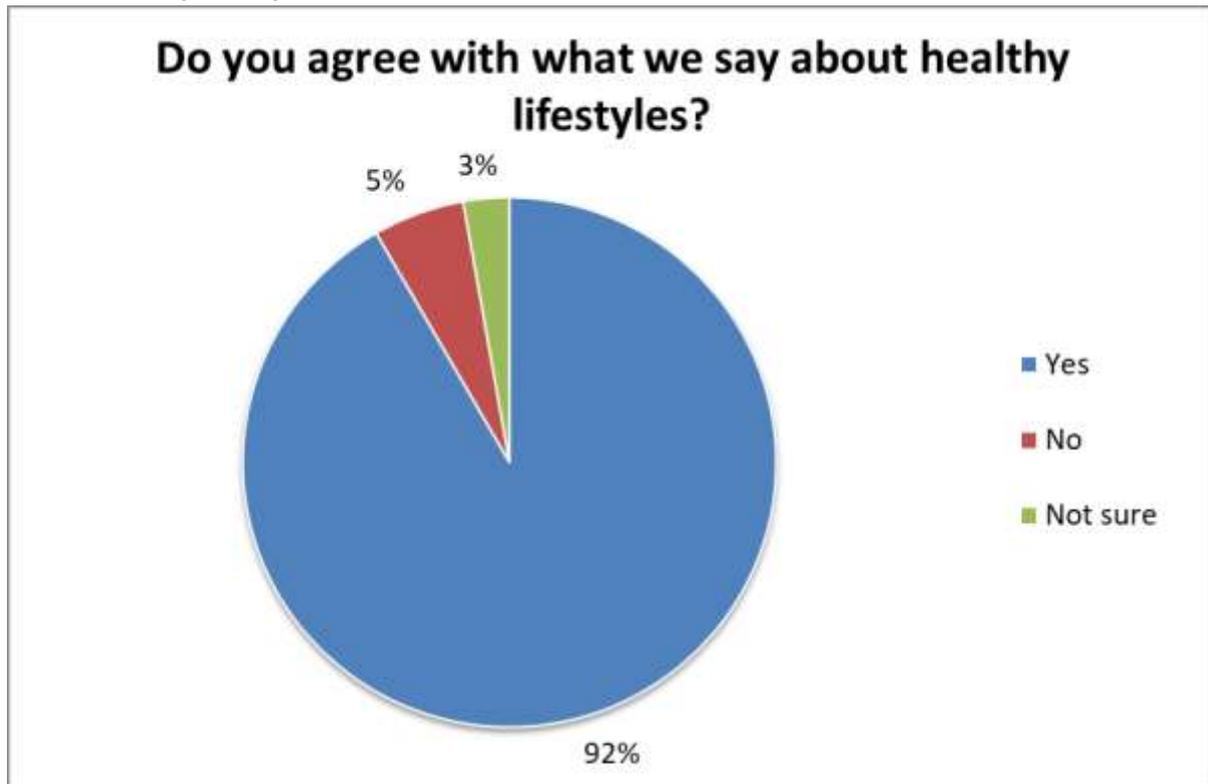
Members of the public

“...misleading and unhelpful statement, "often other illnesses can be missed because doctors only see the disability." Doctors do not only see the disability. This wording should be changed, potentially to, "Sometimes other illness can be missed because healthcare professionals may be distracted by the disability".

“This statement is misleading advice: "Every person with a learning disability should have a health check if they want one. The numbers are improving but can be better.” If this is referring to the annual health check for over 14s with learning disability then it needs to be stated as such. Whereas if this is referring to a general health check-up, then there should be a specific reason for arranging a consultation with a healthcare professional - patient expectations will be unmet when they attempt to book an appointment and they are met with a receptionist undertaking triage and not agreeing to their appointment request.”

“This is not equity of healthcare; this statement is targeting a particular group and actually serving as positive discrimination”

3.2.4 Healthy lifestyles



Comments on healthy lifestyles

People with a learning disability

This topic resulted in comments from people with LD on support for maintaining a healthy lifestyle, understanding what that meant for people, medication and health and fitness activity.

Medication and its side effects were on people's minds;

"Healthy lifestyles are very important i.e. eating, drinking etc., it should be encouraged by staff in care homes and when taking service users out to eat at time I feel my son, living in care, is (on) too much medication; he suffers a lot from side effect(s) of medication."

"I am happy with medication and I have flu jab."

"I am concerned that some medication will be stopped/reduced and could cause difficulties."

Understanding of and support to achieve and maintain a healthy lifestyle were important to people;

"Yes, it is important to understand about healthy lifestyle changes and disability, should have classes to explain or day centre."

"People with learning disability should be better supported."

“Support needs to improve so that I can maintain a healthy lifestyle.”

“Some support workers don’t want to support you with exercise and flu jabs.”

“Initially, leisure centre time allocated to the disabled may help with encouraging them to take exercise in a strange environment. Often people with any disability have been abused through bullying, intimidation and humiliation. So a professional and softly, softly approach may be more beneficial.”

“They need to make information easier. I like volunteer work because it gives me something to do, but I can’t do the fill (forms).”

“Healthy eating - people should have the right support have to have a healthy meal each day.”

Good access to health and fitness facilities makes a difference;

“Some pools don’t have easy access for people with wheelchairs and walking sticks.”

“I want to go swimming.”

“I like going to a special swimming group I like gardening to keep fit.”

One respondent felt it was important to remember people’s own choices and to avoid pressuring them;

“It is (the individual’s) choice if they want to be healthy, it should not be forced on them.”

“Yes in some ways a healthy life style is important. But a person with learning disabilities has other agendas. It is more important that they are supported and cared for, whilst respecting their own preferences. Healthy life styles come through example, trust and encouragement for support/key workers or health care professionals.”

“I feel pressured to be healthy and eating healthy and it’s making me want to get addicted to laxatives to lose weight again.”

Family members/carers

Family members and carers for people with LD were concerned about medication and its management;

“Chemist could put prescriptions in a day by day use box.”

“Some LD patients are receiving their medication by delivery from the pharmacy. The Patient Information Leaflet and the original packaging (are) often not included in the delivery. Pills are put in dosset boxes with no clear labelling. The patient has no opportunity to discuss their medicine with their pharmacist and the support workers have not got a clue about drug safety.”

“Delighted you recognise over medicating as a cause of concern.”

“A public health promotion about safe use of medicines and the importance of taking medication as prescribed and reporting adverse drug and device reactions would be great.”

“Over medication is a real issue. Professionals MUST be REQUIRED to investigate the background and triggers of challenging behaviours and not simply to increase medication, which currently happens ALL the time.”

Support to achieve and maintain healthy lifestyles were reflected by this group too;

“If you want to promote healthy eating focus on educating the teaching assistants and support workers.”

There was some concern about cultural and religious practices affecting the care of people with LD;

“Religious organisations in Leicester are not inclusive for people with learning disabilities and their families. Devoutly religious parents feel ostracised by the attitudes of their religious community.”

“People who want to support people with learning disabilities need to show their faces. Covering the mouth prevents someone lip reading and distorts speech and facial recognition is an essential part of safeguarding.”

Facilities and access to fitness activities was also mentioned;

“More recreational services need to be held at community centres with good accessibility for all. Mosaic and other organisations who manage direct payments could be using existing community facilities more often. With grants drying up these centres need secure bookings to avoid closure and cuts.”

Service providers, professionals and commissioners

This group of respondents reflected the others, and demonstrated the effects of unhealthy living and reliance upon medication;

“Unavoidable ¹ deaths for individuals with learning disability (are) making people more aware that changes need to happen, whether the individual is in supported living or residential they should be encouraged to eat healthy and to go for health checks and be better supported to manage any long term conditions; more support is needed.”

“In relation to the issue of over-medication, I think that more emphasis needs to be placed on understanding why someone might be prescribed medication in the first place, and looking at what else could be offered to meet their needs. For example a referral to community nursing to help someone learn to cope with their anxiety, rather than prescribing medication, or referring to psychology for trauma work if the person has experienced difficult things in their past which may be impacting on their sleep/anxiety levels/ability to relate well to others around them. Medication alone

¹ This may be an error on data entry; intention may have been to say ‘avoidable deaths’.

often does not resolve the underlying difficulties that someone is experiencing, and brings with it the potential for more difficulties (e.g. side effects).

The need for access to adequate support was acknowledged;

“People who live in the community, do not always have enough support hours to ensure that they can plan a healthy food shop and then be supported to cook a healthy meal - 30 minutes is not enough time for someone to be properly engaged in cooking a meal, it takes that long just to boil spuds!”

“...ensure that people with learning disabilities are looked after not only by everyday people but by health specialists as well.”

“Healthy lifestyles (are) for every one and that includes workers. It is recognised nationally that this is not just an issue for people with disabilities, but to support them properly education is key in this area including support workers and family as they will often have a role to play.”

“Will there be an inclusion officer at public exercise providers who can support people with learning disabilities access facilities independently?”

“We need to ensure that any DNR's in place have been done with the full understanding of the service user and their families. Does the service user understand and have the mental capacity to sign this document.”

Influences in the community were a concern, with unhealthy fast-food outlets being easily available but access to fitness facilities perhaps not so much;

“I was involved in supporting people to access Leisure services, but it seems that there needs to be more around encouraging greater access.”

“Close McDonalds!”

Effective joined-up working across organisations and organisational integrity also have an influence;

“More joint working is needed to ensure that this is done. Work with LD nurses, etc. as standard. It can be difficult to find out information about service users' health needs.”

“Providers should all be expected to sign up to the LD Health Charter and complete self-assessment.”

General comments included;

“The proof will be in the delivery. I like that it is seen as a priority, but we need to recognise that more needs to be done to promote healthy lifestyles.”

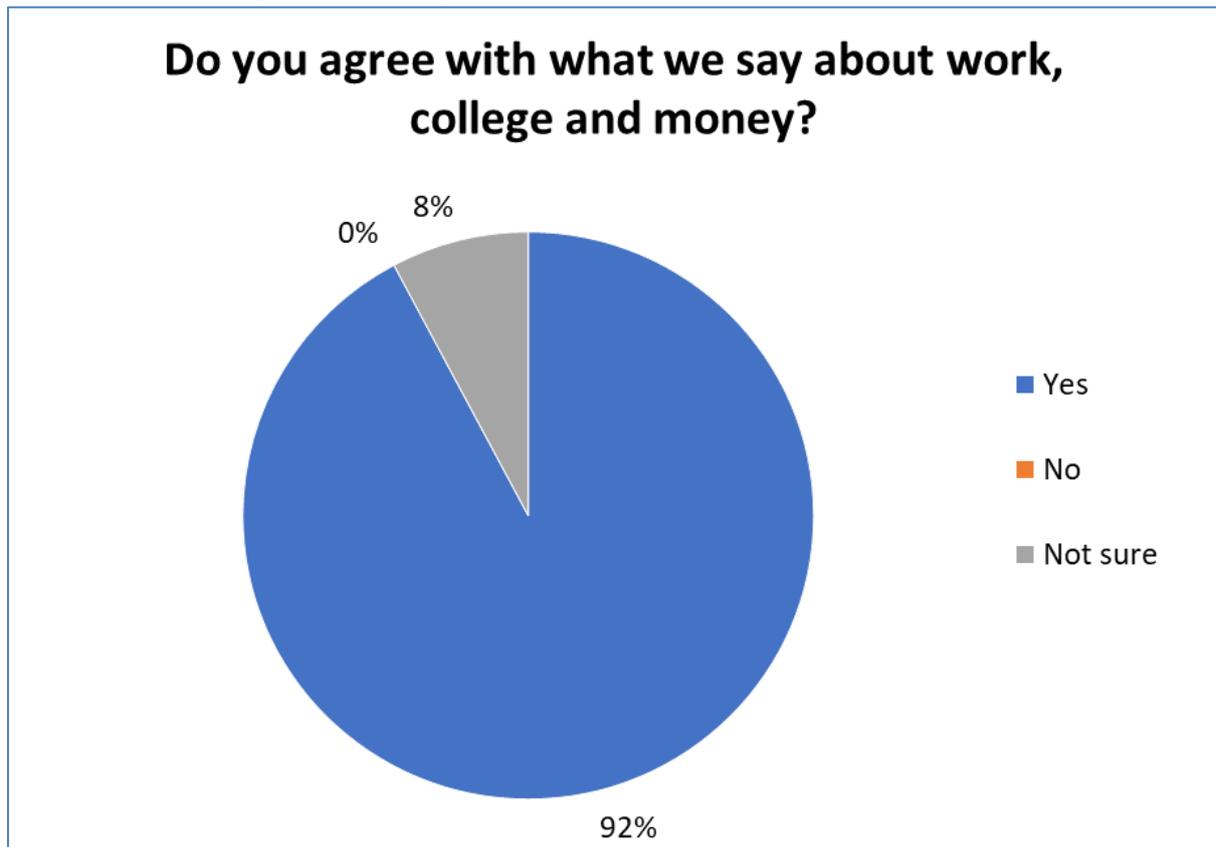
“Circumstances, families, up-bringing, education, money and meeting criteria, is what it boils down to.”

Members of the public

One comment was received, on leisure facilities;

“It is imperative that public health continues to provide the current amount of leisure facilities within the city so it give(s) choices for everyone.”

3.2.5 Work, College and Money



Comments on work, college and money

People with a learning disability

Accessibility was a thread through this topic for people with LD, particularly with form-filling;

“We definitely need a lot more support at Jobcentre especially with all the changes and form filling, it’s hard enough as it is.”

Some Jobcentre’s send forms that are hard to fill in, they should have easy read formats with pictures.”

“There is not much opportunity few people with learning disabilities, easy read/accessible forms are a good idea.”

“They should have the right support in place.”

This group felt that staff and organisations working with people needed to have a greater understanding of interactions with them and the effects this can have;

“It needs to be a “bespoke” service. D.W.P. staff have little or no understanding of the needs of disabled people, let alone those with learning disabilities or mental health issues. Training and improving staff people skills is desperately needed, and soon.”

“Earlier intervention to plan work or college ambitions may not be possible. People with learning disabilities, struggle with pressure applied from external sources. You have to work with them at (their) pace, not your own agenda. For instance, I personally struggle with new information. I have to read it. Read and read it again and again, then try to demonstrate to someone else that I understand. On a good day, it may be manageable, on bad days, impossible. Care staff, support workers, council staff and health care professionals need to appreciate that they need to approach topics about work, college and money with care.”

“Don’t like universal credit pressuring me to get a job.”

“Sometimes people don't know how to talk to people with LD.”

People with LD have ambition and want to achieve, and this should be supported and encouraged;

“I went college and volunteered before. I would like to do more art and crafts and IT work.”

“There needs to be more places to volunteer.”

“There are not enough courses or work experience opportunities. Encourage other companies to work experience e.g. costa coffee.”

“It’s important that people who volunteer get travel expenses as they shouldn’t be out of pocket. It’s important that volunteering give you experience that could lead to a job.”

College courses were valuable and appreciated;

“WEA, brilliant baking course.”

“College really good.”

Family members/carers

Again, accessibility for people with LD (or lack of it) was high on the list of priorities for family members and carers;

“Job application forms are impossible for people who can't read and help may be needed.”

“Depends on the level of so-called learning difficulties and the ability to make rational choices, otherwise it will only pander to the (more able) and those better supported.”

Opportunities for people with LD needed to be matched to and appropriate to their individual capacity and skill set;

“Widening the view of what someone with LD can and can't do. My son is great at clearing tables but would not be suited to hotel and catering work because he regularly puts his hands in his mouth and will drink/eat left overs.”

“I have epilepsy so there are loads of jobs I can't do. I firmly believe that I should have been supported to find a suitable career within my limitations. The constant focus on 'you can do whatever you want' is damaging as dreams are regularly shattered.”

“Too many basic jobs now have additional responsibilities like health and safety monitoring, form filling or lone working, this excludes many people with LD who have challenges with comprehension, literacy and responsibility. They're fine with the practical elements of the role.”

“Look at what is appropriate for (the person with LD's) needs, for a 30-40 miles radius.”

Some opportunities were felt to be something other than they were stated to be;

“I am concerned that many employers are offering voluntary work experience to people with LD to save on wages.”

“Zero hour contracts are not appropriate for many people with LD and certainly not suitable for carers.”

“2 months ago my son was doing a BTEC Entry level ICT course. He was fine with IT and was level or better than his peers. He didn't pass his 6 week trial due to the comprehension required by the BTEC. There wasn't an alternative. Now his curriculum is non-existent, there is very little work in a formal classroom environment so he is losing the ability to be comfortable and focused in lessons. They take day trips for no reason other than 'something to do'. My son was programming animations, designing leaflets and learning Office software. He was learning useful skills and now he's not.”

Carers felt that information and procedures were overly complex, dispersed or misdirected;

“(It is) ridiculous that I need to get a sick note from my son's GP to say he can't search for work for 35 hours per week when he is in full time education and has an EHCP outlining his complex needs and necessary support. DWP staff don't even speak to my son they speak to me yet they still need more evidence.”

“It would be great if there was a booklet given to family carers listing all the things we need to get in place. e.g. bank account, power of attorney, DWP applications, tax credits and child benefit ending, what to expect regarding changes to the families current benefits.”

One carer felt that something crucial was being missed in education and preparation for employment;

“If (the college) truly wants to support SEN students to transition to further education and prepare for the workplace they need to recognise that ICT exists in every job, every application, every FE course and that they need to be offering this to people with LD.”

Service providers, professionals and commissioners

This group also felt that assessment and procedure was lacking in some organisations;

“DWP assessors need much more information and understanding. Asking someone about dressing for instance requires a lot of exploring rather than accepting the first answer.”

“A better look at what is beneficial for the individual.”

Access to real, meaningful opportunities was key and information on these should be more widely available;

“Real' outcomes for many young people with learning difficulties and other SEND leaving FE college are very, very poor. There needs to be a city wide commitment to ensuring real work opportunities exist for these young people including those with more severe and complex learning difficulties.”

“Can we know who the disability confident employers are? Providers should actively work to ensure there are paid and voluntary opportunities for the people they support. We are fortunate to be able to provide paid employment to several of the people we support in Leicester e.g. cleaning opportunities. We also have a peer review scheme where people supported are paid to be part of quality assurance cycle and take part in service audits.”

“This is around people being given appropriate opportunities. LCC (Leicestershire County Council) is a large employer; what percentage do we have of employees with disabilities, as we should be the trail-blazers in this area?”

Crucially, this included how applications were handled by employers;

“When people with learning disabilities apply for jobs, their application needs to be look(ed) at properly and not just scanned over and then thrown to the side, they have the right to have the opportunity to show what they are capable of doing and not just pushed aside and they also should not be bullied at work because of their disability.”

Support to complete forms and understand information was very important to this group;

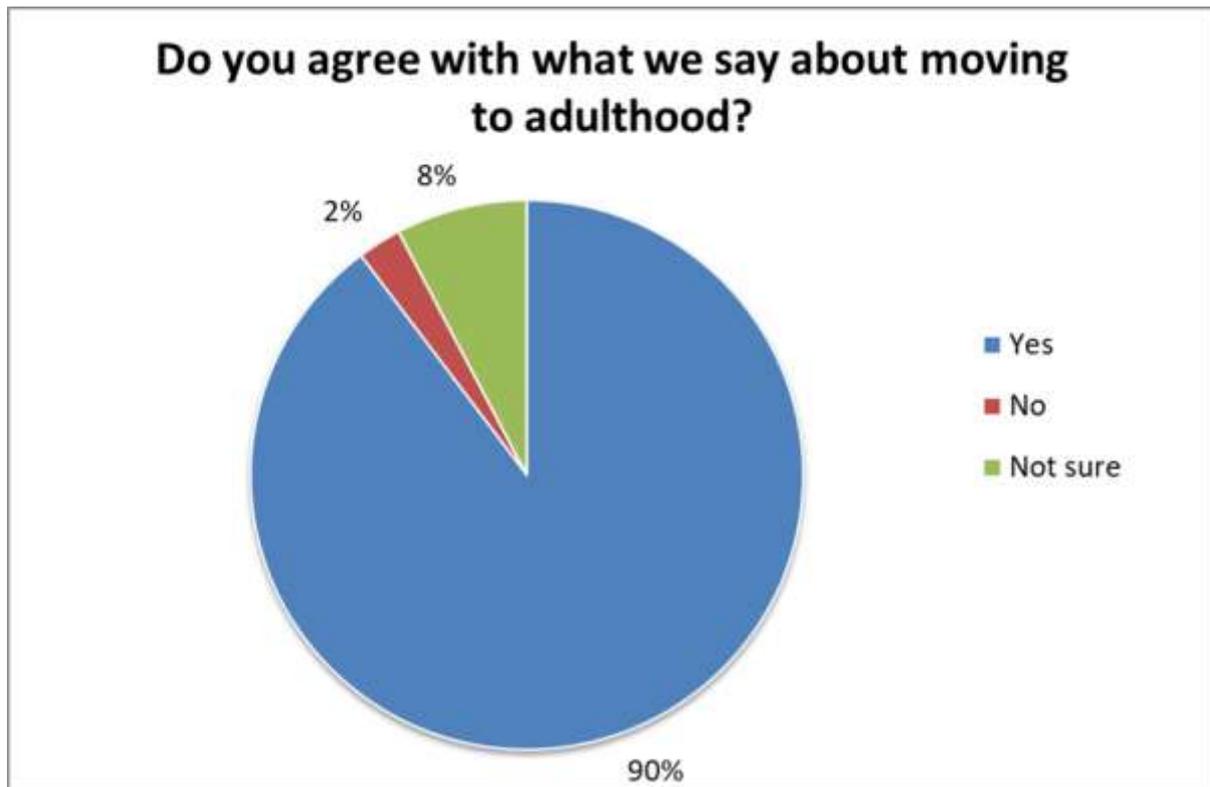
“More support for applying for a job or wanting to access college courses, more opportunity to volunteer and extra support needed when they do, easy read versions of application forms should be made available.”

“Support for meaningful activity/employment is vital.”

Members of the public

“Good specific strategy aims.”

3.2.6 Transitions into adulthood



Comments on moving into adulthood

People with a learning disability

People with LD felt this was a challenging area for them and that it was important to plan and acknowledge this early on;

“I think moving from child and transitioning (to) adult is very hard; need a lot more support in schools before the age of 16.”

“Children needs help and support with transitioning and (what is) the best for them.”

“Should be more options for those in transition. A good plan is a good idea.”

“Yes, children need good adulthood.”

This included information being provided proactively;

"I didn't know anything about (benefits) when I left college and it was hard to find out."

Joined-up working between providers and organisations and the support they provided was seen as vital;

"Whatever the reason for a person's learning disability, the transition into adult care should be seamless. It should involve proactive communication between agencies and services, involvement of the family and the person themselves."

"Most importantly, diagnosis should be understood and read by all involved, to discover the best way of moving forward. In some cases, the client may not ever be able to live independently. They may have the mental age of a child, for life; with all the variables in between. All providers need to be as informed and knowledgeable as they can be, before making or encouraging big life style changes."

"16-23 years of age without a social worker."

"Planning for the right housing and support for people coming through transition as the need will grow."

"Right volunteering opportunities and jobs for young people."

Respondents were concerned that their carers should be considered in this too;

"The client may also need protection from "the world" in general, because of their condition. Above all, these things should be done with compassion. Many parents/families of people with learning problems have been the only protector/carers of the person. So their feelings and ideas need to be included."

Family members/carers

Some respondents from this group felt they were not being taken as seriously as they should;

"Please consider Parent Carers as professionals. Parent carers need to be able to work with professionals without getting the feeling they are inferior. Medical professionals are the worst offenders of this elitist attitude, they are also the most difficult to challenge."

Partnership working and a person-centred approach was important for family carers;

"There needs to be a cross over period between 18 & 25 where services work hand in hand to transition children into adult services. A simply handover at age 18 from children to adult services is not workable due to the differing criteria's to meet thresholds for services. Particularly poor is children to adult mental health services."

"Promote a social responsibility to safeguard the vulnerable. Every citizen should feel supported to raise concerns. Staff need adequate whistle-blower protection and support to report concerns."

“Needs to be agreed timescales that (are) regularly reviewed to keep things on target.”

“Leicester City Council should not give grants or consent to planning applications to individuals and organisations that do not have adequate equality, accessibility and safeguarding policy.”

Service providers, professionals and commissioners

This group felt too that there was an absence of clarity for people and their carers on navigating services, funding issues and a lack of joined-up services;

“Parents and young people need a road map of how to navigate adult services after having been in children's services”

“Better communication and working together between child and adult services, so that there is a smooth transition and no loss of services.”

“This is the most important time; transitions need more money than they currently have, good support to move from children's services with positive outcomes at this stage set the tone for people's experiences and chances of success.”

“...look at the need prior to being 18 not just before.”

“Early preparation and planning needs to occur across all services.”

More, earlier and clearer information on services was needed to foster a greater understanding of changes;

“Transition to be explained better, because they lose so much.”

“Agree that working with younger people from an earlier age is key as children come into adult services and this is a real change of which can be difficult for them to adjust. I'm intrigued as to why 14 appears to be given, as children mature in different ages, but the principal is the same; we need to better equip children for what lies ahead when they transfer into adult services.”

It was felt that proposals offered real improvement and that for some, transition was working well;

“If the outcomes stated in the draft strategy can be achieved then the support for these young people will have improved significantly.”

“Our experience of young people moving into adult services has been a positive one. Ideally we need as much time as possible to properly plan transitions.”

“This is a really important time for young people and so important to get right, if we offer the supported living model as part of respite provisions it will help prepare young people for the future. We need more provision for young people to try out the supported living model, to enable them to make an informed choice.”

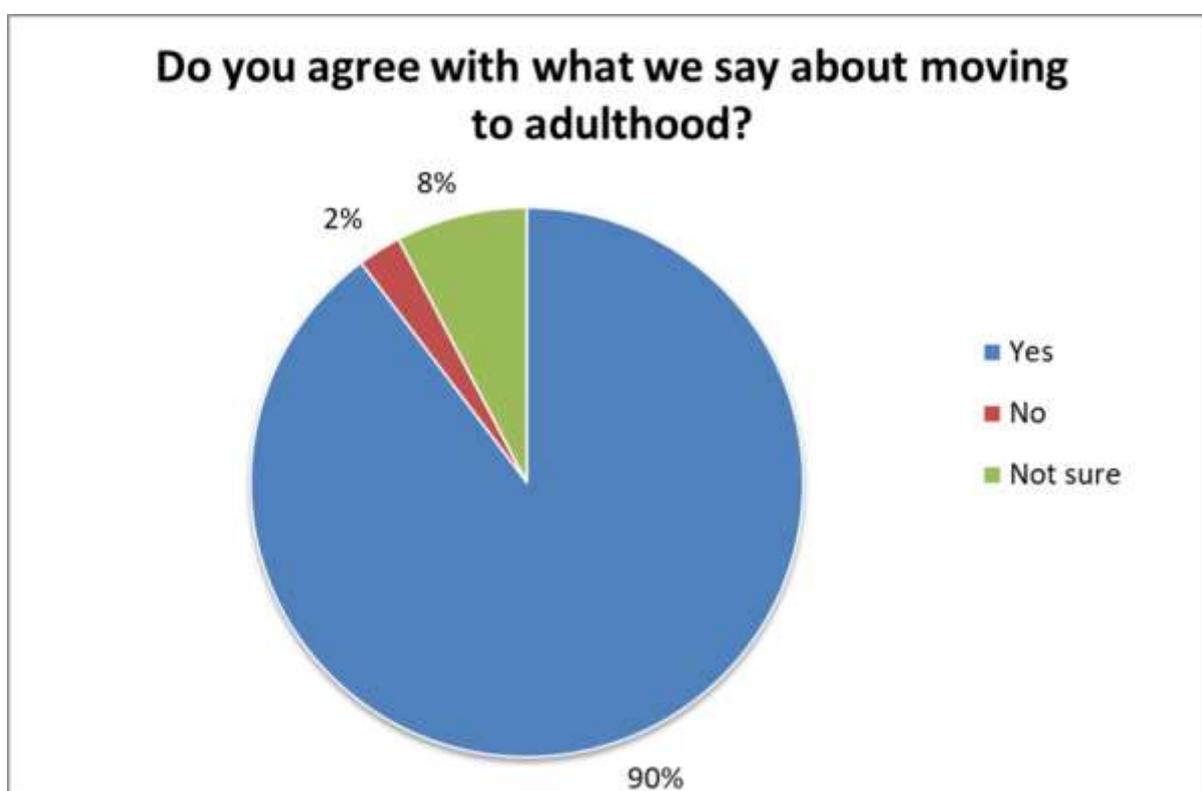
“Leicestershire NHS Partnership Trust are proposing the introduction of an interim phase from 17-24 ‘adolescent’ group, to ease transition from children’s services to adult services.”

Members of the public

A comment from a member of the public highlighted perceived gaps in support;

“I believe that when children leave the system at 19 there is little or no help for them, putting an enormous strain upon their families.”

3.2.7 Support for our carers



Comments on support for carers

People with a learning disability

People with LD felt strongly about carers receiving adequate support;

“As (a person with) a long-term, older, full-time carer we do not get much support or help especially respite for ourselves. Carers should be valued more. I do hope very much the plan set out for carers will make a great difference in our lives”

“We definitely need more and more support for carers, especially with all the changes and challenges ahead.”

“Carers need good support; a lot of stress...carers are not listened to much. Carers should be on the GP register.”

“Support for carers is critical. The carers are the ones who struggle each day, to provide a clean, safe environment, as well as a good place to live. They are and should always be the first port of call when questions need answering about the client’s care. Offering practical help as well as counselling and a listening ear, can make a huge difference. Carers often become ill and exhausted and need to be offered proper, appropriate breaks. The carer also needs to know where the person they care for is going, what it is like and have reassurance that the client will be looked after properly.”

“Carers need (to be enabled) to do their job good.”

“Even offering a service that calls the carer on the phone once a week, to have a chat and catch up, can make all the difference.”

Carers themselves were often felt by those they cared for to be underestimated or undervalued by services;

“Carers are often invisible. They are often more than excellent at what they do and take their loved one's needs in that bespoke and compassionate way. Carers can often feel left out, excluded when it comes to information about the person with disability. Yet it is often the carer who will be asked to explain what other healthcare professionals have said after an appointment.

“Communication with carers is vital. A way of encouraging carers to obtain power of attorney, (should be provided) if needed.”

“G.P.s should be actively encouraging carers to register. The problem is they may not understand why that is important. They may also be receiving benefits themselves, and worried that if they register as a carer, it will affect those benefits.”

People felt it was positive that support for carers was being considered;

“I think this is really good.”

“We should value our carers.”

Family members/carers

Family members and carers felt that carers’ needs for support were being only partially considered;

“Quite often a carer is caring for more than one family member, so do not get any proper respite.”

“Young carers need to be supported. They look after their relatives with SEN, sometimes they are struggling at school or work and need to be recognised for the job they do.”

Some felt that there were significant challenges to success;

"I appreciate both the sentiment and work that has gone into this, but omelettes cannot be made without eggs; they are an essential part of the omelette. Likewise, money and support are essential to all these aims and objectives mentioned. Both general attitudes and long-term political intentions have to be changed."

"Some carers are not fit to be carers."

"Many carers are also disabled. There is often more than one sibling with a disability who are all looked after by the parent carer."

Engagement with and understanding of carers' needs amongst and providers was questioned;

"Is anyone at NHS Leicester really interested in carers? How does Better Care Together engage with carers? How can the void in the relationship between council and the various NHS organisations, CCGs, trusts be resolved?"

"Professionals supporting carers should be able to advise, or go and give timescales to carer and get answer(s) back to help support."

"We are in our seventies and generally speaking I can look after my daughter who needs very high levels of medical and general care. I do not want or need teams of people coming to the house regularly, but there are now times when I need emergency care, sometimes only for one or two days. So far I have coped, but it seems the only choices are nothing (except a short break service which is fine but is booked for a year in advance) or two people coming in every day and these people would need to have a high level of training. This must be expensive."

"Carers MUST be offered an assessment of their own needs, irrespective of their income or background. This should be mandatory as soon as someone is known to be a carer by the authorities, i.e. a register of carers is required to be set up."

Service providers, professionals and commissioners

Providers, professionals and commissioners felt that support for the carer should be more fully considered and provided based on the carer's needs, not those of the person they care for;

"I would say that respite for carers shouldn't be restricted to those caring for people with complex and profound and multiple LD. Caring for someone long term (with a) LD (even a mild LD) can be difficult and can have a huge impact on carers' lives. I feel that respite care should be considered dependent on the need of the carer, rather than on the level of LD."

"Welfare Rights for Carers is crucial & this is something that has disappeared."

"Respite is a crucial issue & it is going to get more problematic as Health reduces the number of people who can access health respite (as they reduce people who have spilt health & social care funding)."

"Access to ongoing training, support groups and talks is really valuable and the council should continue to support this."

Others felt it was important not to lose focus on the needs and opinions of person being cared for;

“Whilst I agree carers have a great role to play we need to be mindful that we don't focus on them, as the person with the voice should be the service user. Whilst carers' roles are vital, we need to be mindful that actually they may have different thought than the actual individual. I fully appreciate the vital work formal informal careers do.”

Respite care services provided essential support for carers...

“The issue for respite for people with complex needs has been going on for years, this needs to be prioritised. Carers who support people with high complex needs need quality breaks, where they have full confidence in being able to know the person is receiving good quality care to enable them to fully switch and relax ensuring they have a quality break.”

...but others felt this was under threat;

“Quite ironic when we are looking at closing the healthcare short breaks services. Families (need) more, not less.”

“Limited by availability of places dependent on single sex, long-term/uncertain duration of stays, lack of respite.”

It was felt to be important that information was widely shared across services;

“Can schools be made aware of where parents can go for what needs and up-to-date contact details and criteria be available widely.”

Members of the public

One person felt more precision was necessary;

“Ambiguous statement: “professionals need to get better at giving carers the opportunity to be put on a GP's carers register.” Which professionals, and when should carers be given this opportunity? What should the procedure be? Shouldn't the onus be on the carer to present (themselves) as the carer and make the necessary disclosure to the GP surgery, rather than GP surgery having to ask everyone if they are a carer for anyone with learning disabilities.”

3.3. Public Meetings, Service User Groups, Interviews, Letters

3.3.1. Public Meetings

28th February Leicester City Town Hall 10:00 – 12:00

Two people attended the meeting, both were carers and one person was only able to stay for part of the meeting. The proposed strategy was supported, the following points were raised.

- Edibility decisions seemed to be complicated and changeable.
- Social care system is very difficult to negotiate and would be very hard for people with mild or moderate learning disability who do when they have no body to advocate for them and get lost through the cracks.
- Supported living options should be a genuine choice and not motivated by savings.
- Forms for benefit claims and other assessment forms are far too wordy and very lengthy documents that are hard to understand and complete for many carers.
- There is a gap in understanding what having a learning disability actually means for a person amongst many services and professionals.
- Case management process of social work teams mean there are negative experiences due to the inconstancy of care. Workers assigned to individuals do not have historic background of person and a lot of time is wasted by asking questions that have already been answered.
- Supported living service quality must be consistent feedback is that some are good and some are not so good and it seems to be a lottery as to the quality of support people get.
- Assurances that people's social circle is considered, and support considers maintaining these relationships is vital to emotional wellbeing and support.
- Emotional support reasons are very difficult to quantify in hours, which is how support packages are worked out, this would need to be looked at.
- Health action plans were not received although people were getting LD health checks regularly.
- Carers need a lot of support with making claims for benefits and other welfare rights issues.

1st March Leicester City town Hall 10:30 – 12:30

Three people attended this meeting. There were two family carers and one person with a learning disability. All three agreed with the proposed strategy and added the following points.

- Understanding all different cultures and wording needs to be sensitive to people's understanding and attitudes towards LD across different backgrounds
- Future planning for cared for person, what practical support is there when parents and carers pass on. This will be important for people with a learning disability.
- There needs to be specialist LD bereavement support or an assurance that health and social care staff have skills to provide this.
- PIP and other DWP related assessors need to all have same level of understanding and application of learning disability issues and social model of care.
- PIP outcomes are very inconsistent. PIP scores for people with very similar needs are too inconsistent meaning unequal levels of benefits are being received.
- Hospital care is not geared towards people with a learning disability who too often experience 'spoken about' and not 'spoken too' whilst present.
- Health action plans do not have much detail and it is unclear what the purpose of the plans are.

- Health action plans should have a communication section within.
- Systems need to ensure that details of people's communication needs are clear and accommodated.
- Appropriate methods of communication or the most appropriate person to speak to about appointments, meetings, or scheduled health consultation must be clear and followed.
- Message about free flu jabs for ALL people with a learning disability is not clear and consistently followed across Leicester.

6th March Brite Centre, Braunston, 10:00 – 12:00

Three people attended this meeting. Two were family carers and one person worked for a charitable organisation which focus' on promoting employment opportunities.

- People with lower level needs are more vulnerable to scams, postal scams, so trading standards campaigns need to be accessible for people with a learning disability.
- More needs to be done to support people with less physical support but have more vulnerability due to intellectually based needs from financial abuse and being taken advantage of.
- Employment opportunities need to be improved.
- More engagement with voluntary sector about offering voluntary and paid employment opportunities to people with a learning disability.

7th March Brite Centre, Braunston 10:00 – 12:00

One person attended who was a full time family carer.

- Key issues were around housing related support. More training is needed for people working in housing.
- Carer stress needs to be understood by housing support services.
- The needs of people with learning disabilities and hidden disabilities are not considered by people by housing staff when looking at options.

14th March Quaker Meeting House, Evington, 14:00 –16:00

The proposed strategy was supported, the following points were raised.

- No attendees for this meeting

15th March Quaker Meeting House, Evington, 14:00 – 16:00

Two people attended this meeting, this was a paid shared lives carer and a person with a learning disability. The proposed strategy was supported, the following points were raised

- Independence should always be promised. If a person with a learning disability feels they can attend appointments, they should not be told they MUST bring a carer with them.
- Share lives services are effective and should be promoted.

19th March Peepul Centre, Belgrave, 10:30 – 12:30

There were 10 people at this meeting most were family carers. One person was a service user attending with a paid carer. There was also a paid carer from Leicestershire who attended the session. The proposed strategy was supported, the following points were raised. Key concerns were how the objectives of the plan would be met.

- An Action plan is needed and there should be accountability
- There needs to be a carers board that represents the views of all carers not just the ones connected to the organisation that has a contract with the city council.
- Health checks are not always happening.
- Health action plans are not being produced.
- Continuing health care decisions are being made and it is hard to challenge the decision.
- There are carers paying organisations large sums of money to complete benefit forms such as PIP.
- There were some concerns that people cannot complain and that they will lose support hours.
- Some carers are not confident that their concerns will be listen to and do not want to raise complaints because they feel they may lose the support they currently have

21st March Peepul Centre, Belgrave, 10:30 - 12:30

- The proposed strategy was supported, the following points were raised.
- Care provider raised an issue that the information from the council is not right at times. Need to get better at information sharing.
- Hidden disability – 1 carer talked about her son with hidden disability and working.
- Issue about employer's awareness of learning disability was raised.
- Reasonable adjustments
- Good days and bad days – become difficult
- Healthy relationships to be included under healthy lifestyle.
- Evening activities for adults with learning disability e.g. disco
- Health and social care workers – it's challenging people's support needs should always meet both emotional and physical needs.
- Dual diagnosis (people who have multiple diagnosis) and assessor's skills – learning disability, mental health and autism.
- Transitions – Planning for adulthood should start earlier.
- People not seeing themselves as carers, educating people.
- Criminal justice and probation service - Learning disability awareness

- Self-medication and Substance misuse (alcohol + exploitation) – how do you manage and safeguarding

3rd April, Voluntary Action Leicester, 18:00 – 20:00

One person attended this meeting. The strategy priorities were all agreed. Some additional points were made. The proposed strategy was supported, the following points were raised.

11th April, Hastings Road Day Centre, 11:00 – 13:00

12 people attended there were 8 family carers, 2 paid carers and 2 people with a learning disability. The proposed strategy was supported, the following additional points were raised.

- More co-production across all areas is needed
- Clarity is needed on what person centred should mean and what people should expect from a person-centred approach.
- Choice and person centred under social care – it was suggested to come up with a list of what is meant by choice and person centred. My choice was discussed. It was suggested to have an app rather than website.
- It was suggested that there is no point having a strategy document every 3 to 5 years if there is no monitoring group set up for carers every 6 months to 1 year.
- It is important for carers to be able to get more involved.
- There was requesting to have annual report/yearly update on LD strategy every year.
- There was a feeling that care management were not listening to carers
- Safeguarding concerns need to be followed up and family members need to be fully informed throughout the process.
- More effective communication methods such as social media platforms should be embraced to share information with families.
- HRDC service users have good choice but not little choice in community settings.
- Health checks are good but there needs to be more detailed information provided.
- None of the attendees were aware of health action plans.
- Staff at hospitals need to all have skills to enable them to meet the needs of some people with complex needs.
- Quiet room for people with complex is needed at the hospital particularly in A&E
- All sports facilities need to be accessible and there is no hoist at Cossington sports centre
- Some GP surgeries are good at giving flexible GP appointments to carers but not all recognise the need for this.
- Practice managers at the GP surgery should include a message on the first screen to say that special care is needed.
- A carer said that previously until 2012 there were 2 nurses at HRDC Tracy and Angela who were helpful and it was useful to speak to them once a month. But now nobody has done service user's weight from last 7 years.
- No consistency with what social care case understanding each time a carer contacts about a person needs they have to repeat information that is already

3.3.2. User Group Meetings attended

14th & 28th March 'The Carers Centre'

The Carers Centre supports carers across Leicester and Leicestershire and have a specific group for carers of people with a learning disability. The proposed strategy was supported, the following points were raised.

- Housing need to understand issues around LD MH and Autism when looking at applications
- Council phones are not people friendly
- Choice how DRE is calculated means that a lot of expenses for people with LD are not seen as DRE
- Care Act applies to the council not just social care
- If person has something like autism you need to think autism not just learning disabled/ mental health etc
- Housing – Vulnerability of where people live e.g hate crime,
- Housing need to take into account care needs e.g they may need to live near family
- Regular meetings with senior officers and senior social workers to keep in touch with carers
- Disability related expenses do not take into account need of people who have LD MH and Autism
- Need to know advocates are independent of commissioners and service providers
- Clearing should only be the starting point
- Targeted training in required for all professionals
- To access places where do you leave loved ones
- Finance driven not needs driven
- Need to keep specialist teams such as learning disabilities
- Remember how carers have a lot of knowledge about a person with learning disabilities please listen to them
- Families are not listening to in most cases they know more about their own
- Disability related expenses is not enough
- For learning disability and autism cases carers must be listened to and involved with developing care plan and benefit claims
- Team leaders and key strategic officers must meet carers more often to hear their issues and concerns

27th February & 22nd March, 'Talk and Listen Group'

The talk and Listen group are organised by the Leicestershire Partnership trust, and provides expert by experience input into local health services, they also undertake recruitment interviews as part of the recruitment process for the learning disability service

All members of this group were supported to complete the survey form. However, there were some additional points that were raised for consideration in the final draft version of this strategy.

- The proposed strategy was supported, the following points were raised.
- Access to public transport more difficult than it should be
- Very difficult to get dentist appointments
- There is not enough choice where to live.
- Accessing gyms can be hard
- More should be done to make sure people understand things that are written in their assessments and support plans
- Hospital care can be sometimes quite poor, when staff do not understand or make assumptions about people with a learning disability not understanding what is going to happen or being said.
- Some people have had experiences where they are treated like 'naughty children'.
- People with a Learning disability need better support and pathways to raise issues that they are not happy about rather than having to go through formal complaints procedures.
- It needs to be easier for people to complain Having a safe way to raise issues that people are not happy about rather than going straight
- People are not receiving health action plans

25th March & 29th April 'We Think Group'

The 'We Think' group and the 'Talk and Listen' group are service user self-advocacy groups. The 'We Think' group includes both paid local leaders and non-paid members, all members have a learning disability and provide expert by experience input into the work of the learning disability partnership board.

'We think' were co-produced the draft strategy, they also completed surveys. The purpose of the meetings was to keep the group up to date with further issues raised during consultation.

3.3.3. Interviews

18th March: Healthwatch Leicester & Leicestershire

Health watch Leicester and Leicestershire are key members of the Leicester City Learning Disability partnership board. A meeting / interview was set up with a health watch board member who also attends the learning disability partnership board.

The proposed strategy was supported. The key additional observations and suggestions included:

- The strategy does well at identifying many of the appropriate priority areas
- The easy read format works very well and gets a clear message across
- There are some other areas that need to be considered for inclusion. In particular a priority within the equal health section needs to include mental health support services to be accessible for people with a learning disability.

- A suggestion that assurances should include a measure that demonstrates professionals are able to identify mental health conditions being presented by people where they also have a learning disability.
- A key observation included having a separate section on social inclusion, this would incorporate some of the objectives detailed in the section for healthy lifestyles.

4. Recommendations

There was an overwhelming majority of respondents who agreed with the strategy aims objectives and the actions suggested to 'make it real'. The general consensus was that whilst the ideas are all appropriate, the difficulty will be in the implementation will be challenging.

Some sceptic views have questioned the ability of the partnership to achieve some of the aims outlined in the strategy document. There was a clear instruction from meetings and surveys that demonstrating what has been achieved should be done on regular basis.

The following recommendations detail additions that will need to be included or strengthened in the strategy document.

- Information needs to be available in a range of formats to meet accessible standards this should include but not be limited to easy read.
- Clear information on alternative ways how to access services if people struggle with systems
- SEN education needs to be age appropriate and build skills not contain behaviours
- Emotional needs to be explicitly referred to in assessments.
- Bereavement services and future planning for when a family carer dies and ensuring the continuity of support for the cared for person needs to be included.
- Access to wider social activities and events needs to be supported by this strategy.
- Access to public transport and the ability to share the best practice and develop skills of public transport staff should be part of this strategy.
- Identifying, treating, and supporting mental ill health for people with a learning disability
- Annual open meetings for people with LD, their families, and other carers, across the city should be held to allow for meaningful engagement and test understand what differences the strategy have made.
- An action plan will need to be developed to drive forward the work of the strategy and provide evidence that organisations are embedding this strategy.

5. Appendix