



Report

August 2021

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1. What is it?

An engagement process which lasted 2 months between 17th May and the 16th July 2021. The Big Conversation was designed to hear from people who have a stake or interest in daytime support for people with a learning disability and/or autism in Merton. 7 stakeholder groups were defined:



- Adults who are supported during the day
- Young people who might need support during the day in the future
- The families/carers of young people who might need day support in the future
- The families/carers of adults who are supported during the day
- Professionals who advise people who get support during the day
- Providers of daytime services
- Providers of services to people who get support during the day e.g. supported living

2. What happened? - overall



A **Reference Group** of people from the 7 stakeholder groups was established and its members guided and supported the work. A **webpage** was set up to share information. [An accessible video](#) was produced to tell people about the Big Conversation and invite them to contribute.

7 electronic **surveys** were set up – each aimed at one of the stakeholder groups. We invited people to complete these online, join a meeting, make a phone call or share their views in other ways. A **communications campaign** supported the process, updating the webpage, issuing press releases, publishing articles and using social media to promote. When people shared information with us verbally or in writing we recorded their contribution on one of the online surveys.

3. What happened? – the detail

With excellent support from local people and organisations we:

Held **face to face meetings** with lots of people including those at Leyton Road, All Saints and JMC and time with people at Special Care and the Willows, supported by therapists and staff. We spent 3 days with Adult Education (RHACC), 2 evenings and one afternoon at Mencap-Aces, Buddies and Café. We spent time at 4 houses which are home to people helped by the Council's supported living service.

Held **online meetings** with Merton Council staff (x 3), parents, carers and Generate Voices. Had **phone meetings** with parents and with a person with a learning disability. We worked with day centre staff to send **paper survey forms** to families (19 returned).

We **promoted the online surveys** and invited people to complete them. Day centre and other staff supported people with a learning disability and/or autism to complete surveys and completed surveys online themselves. Cricket Green and Aurora supported students to complete surveys. Perseid School and Orchard Hill encouraged young people, parents/carers and staff to complete surveys. Members of the Reference Group, including Kids and Adults First shared information through their networks. Merton staff encouraged people to complete the surveys directly, through their networks and social media.



4. Who did we hear from?

In total **381** people contributed to the Big Conversation. Almost **70%** of these were people with lived experience of learning disability and/or autism.

There were responses from:

192 people with lived experience of learning disability and/or autism

- 52 young people – 1 response represented 5 people. 56 in total
- 101 adults – 7 responses represented groups – 42 people. 136 in total

69 family members or carers

- 18 families of young people
- 51 families of adults

120 professionals and support staff

- 51 advising professionals – 1 representing an additional 31 colleagues
- 24 day support providers
- 15 supporters of people who use day services



5. How to read this report

People were amazing and many shared a lot of information about themselves, their experiences and aspirations. Some people shared things that were important only to them and other people shared lots of things. For this reason, we can't just take what people said and turn it into statistics. If we did that then some voices would not be heard. So, in some

places, where this wasn't an issue, we have shared statistics and in others, where it could have been an issue - we have used word clouds to show what people said. Words are weighted in the word clouds, so the bigger the word in the image the more it, or something like it, was said by people.

In the written narrative we have used the following descriptors to give a sense of how many people said the same thing **most people*, **lots of people*, **some people*, **one or two people*.

The orange boxes throughout share direct quotes from people who engaged in the Big Conversation. The quotes link to people under each section heading so if the section is focussed on families the quotes shown in that section will come from family members.

6. What did people say?

We had a huge response from people with personal experience of learning disability and/or autism so we want to focus most on what they said.

People who are or could be supported during the day

Responses came from 192 people with personal experience of learning disability and/or autism. 56 were young people and 136 were adults. Of the people who supplied the information:

- 33 were under 18
- 17 were aged 18 to 25
- 64 were between 25 and 54
- 21 were between 55 and 69
- 6 people were over 70

**Lots of people did more than one thing during the week. They did different things at different times. 45 people attended school, college or another educational environment including Cricket Green, Cheam High School, a private school in Redhill, Ambitious about Autism College, Michael Tippet College and Richmond College. *Lots of the young people had support at school or college from a Teaching Assistant.*

'I do gardening at Share Community. I do acting at Baked Beans. I have a travel buddy. I do volunteering and guitar lessons'

6 people had a job or spent time as a volunteer.

**Lots of people, 68 in total, attended day centres some or part of the week, this included people who spent time at special care. *Most people who attended day centres went to those run by the Council. In addition, *some people were supported by Mencap, Baked Bean, Workshop 305, Wisdom Support, Squad Club, Inspire Sports, Deen City Farm, Share Community Garden and One Trust Tooting. *Some people also got support during the day from family, personal assistants, supported living, shared lives or*

other home based support providers. *One or two people also mentioned support from Child and Adolescent Mental Health Service Team (CAMHS) and therapists.

When asked what they are good at and what is important to them people shared varied skills and interests. Friends and family were important to *most people with sports teams and helping people also mentioned regularly. *One or two people said things like it was important to them to know what was happening, to not feel cold, to have

'I'm good at watering in the garden and I'm good at sawing. I'm good at being confident and telling people how I feel and what I think. Meeting people is important and working with people my own age. I would like to have a job'

'My work with the youth council'

own space, to
go to church

and to have choice in life. *Lots of people said they are good at cooking, IT and the internet, art and craft, dance and performance, maths and sport. *One or two were good at things as diverse as caring for pets, playing with sticks, conversation, Transport for London, puzzles and telling jokes.

What do people like to do during the day



Remember the bigger the word in the image the more people said it or something like it.

We asked **adults** 'how good is the support you get during the day?'

81.5% of respondents said it was good or very good

'I like sensory experiences and when I arrive each day Zoey makes me laugh by throwing paper confetti. That puts a big smile on my face'

Then we asked what people like about the support they get. *Lots of people talked about the relationship they have with staff, the fact that staff know them well,

'It is the only place I meet my friends'

listen to and value them and offer the support that they need. *Lots of people also talked about the support giving them the opportunity to see friends, meet people and socialise. *Some people talked about the activities they enjoy, and others talked about getting the chance to try new things and to learn. *Some people valued the fact that the support enabled them to get out and about, to take trips and feel part of their community. *Some people talked about the enjoyment and the fact that services and supporters offered a chance to have fun and a laugh with others.

'I like coming to JMC. I enjoy music and sensory stories. I also like going out and about on walks with my support worker...'

We asked people what they don't like about the support they get during the day and *lots of people couldn't think of anything. *Some people mentioned the fact that they now have less chance to do the things they did before – unclear if this is as a result of Covid 19 or more general reductions to services or a combination of the two. *Some people mentioned travel and challenges with transport. One person talked about receiving letters that they can't read.

We asked **young people** how much they know about the support they might get in the future.

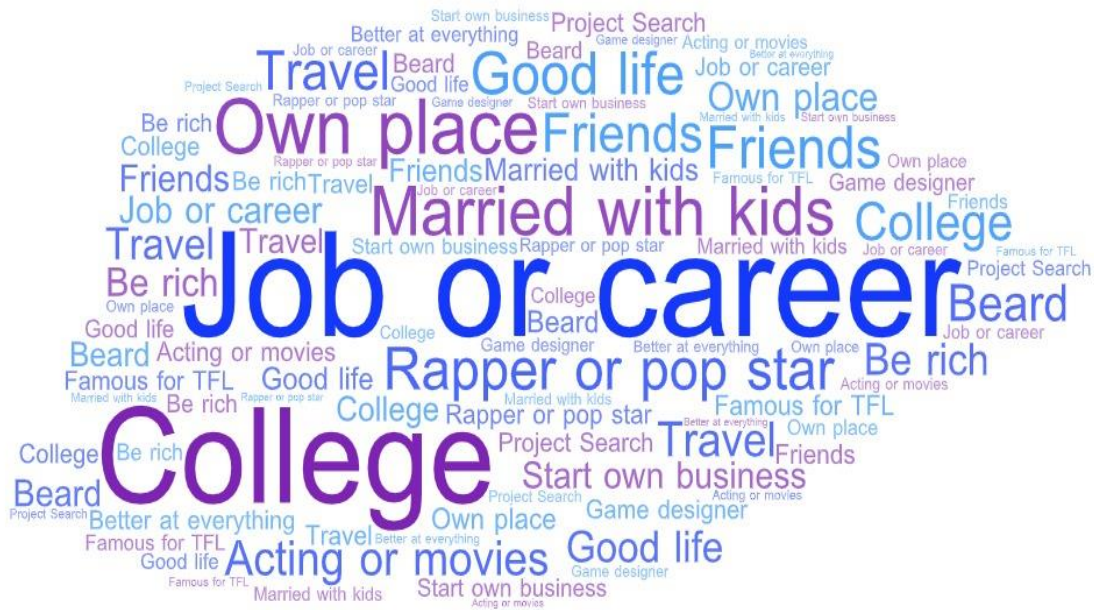
69.5% of people said they know a little or nothing.

'I want my own gluten free café so people who have coeliac like me can have whatever they want'

We asked **young people** about their dreams for the future *lots of people shared aspirations for named jobs, careers and *some people told us about their idea for starting their own business. *Lots wanted to

'I don't know what job I want but I do know I want to have a family, be comfortable and have a nice life'

learn or go to college and *some saw a future on the stage or TV or one which included fame and fortune. *Some people aspired to have their own place and/or marry and have a family. *One of the 51 young people dreamed of attending a day centre.



We asked **adults** about their future dreams. *Lots of people wanted to go on holiday or take trips. *Lots wanted to spend time with friends and family. *Some people shared a dream to spend more time at the day centre. *Some people shared job or volunteering aspirations. *Some people said they were happy. *Some people had no dreams for their future.



When we asked people if they had anything else to share **some people told us how much they love their day centre and how much they wanted it to stay open. People who do not use speech were observed in day centre settings having a warm relationship with the staff that support them. **Some people said they wanted more opportunities to learn, asking for more courses, education or classes. **One person said they need a wheelchair accessible toilet***

'I would like to do more courses'

and **one said that they would not like having to go to different places with different staff each day.*

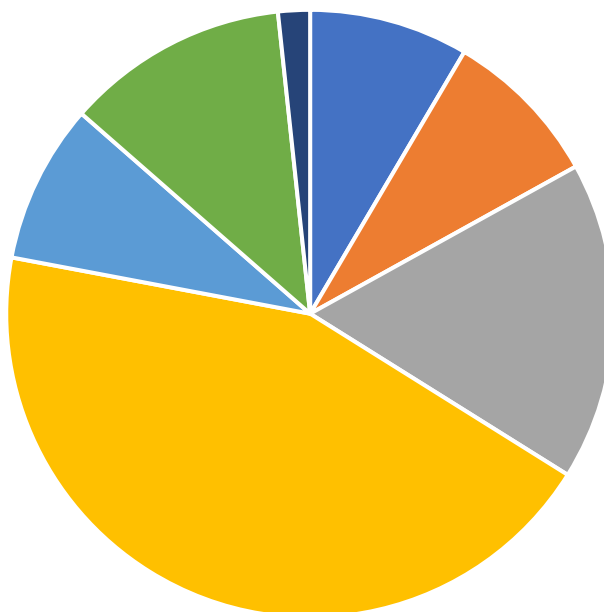
Families

Responses came from 68 people, 18 were the families of younger people and 50 were the families of adults.

Lots of their family members did several different things at different times during the week. 26 people attended day centres and for 22 people these were run by the Council. **Some people, and young people in particular got no support except from family members.



What support does your family member get during the day?



■ School ■ College/training ■ No help ■ Day centre ■ Full time support ■ Direct Payment/PA ■ Volunteers

What does your family member like to do during the day?



What do they like to do on an evening or weekend?



When asked about the help that people need in order to do things. *Some family members, 10 in total, talked about the need for intensive, often one to one support and/or personal care for their son or daughter. *Some talked more about the need for supervision, accompaniment, support and encouragement. *Some people talked about travel and how their loved one needed transport and/or help to get to places. *Some people talked about the need for safe spaces and places where their son or daughter would be welcomed, understood and valued. This was particularly mentioned in relation to people who have Autism. *One or two families highlighted the need for mobility aids and other equipment. *One or two families talked about the need for good information from the Council.

'They are totally dependent on others for help with everything...'



When asked about the impact of the Covid 19 pandemic *lots of people talked about a lack of support and of being left to support their son or daughter alone in often very challenging circumstances. *Lots of people talked about the isolation,

'It has made us more isolated, and my son has gone into his shell'

stress, distress and anxiety experienced by their son or daughter and by themselves and their wider family. They talked about how these issues had resulted in their family

'He has been at JMC most of the time which has been a huge help'

member becoming withdrawn, with issues such as mental health problems and self-harm mentioned by more than one person. *Some people had been unable to access anything online and this brought an added pressure when this was the default approach taken by services and wider society during the pandemic. *One or two people talked about lasting life impacts such as having to give up their job/career or put off a planned house move. The support that day centres and wider services were able to give was mentioned as positive by *more than one person.

'Devastating. All support was withdrawn. School was closed. Our daughter sleeps four hours a night so the rest of the family were at breaking point'

'Back to 5 days at the day centre'

When asked about daytime support for the person they support - in an ideal world there was some difference between the views of families of young people and those of adults. *Lots - 16 in total - of the families of adults talked about their son or daughter being able to attend day centres at least 5 days a week and that this should be in Merton - not out of borough. *Some of the families of young people did talk about the need for structured activities, supported by skilled staff but only one or two mentioned day centres specifically. *Lots of people were clear that as we emerge from the pandemic they wanted to 'get back to normal'.

*Lots of people from both groups talked about a wish for activity to be developmental and purposeful with links made by people to volunteering, work, training and personal development pathways - perhaps linked to colleges and/or adult education. *Lots of people from both groups talked about support at different times of the day and week and more flexible services - offering greater variety and choice that people could dip into or tailor for themselves. *Lots of people from

'Having engaging activities which are building skills, are fun and are confidence boosting, not just 'babysitting' them'



'If my child was fully supported, I'd be able to do other things with confidence, knowing that they are well cared for and having fun'

both groups also talked about the social side of

daytime support requesting help for people to spend time with friends, in smaller groups, hubs and clubs. *One or two people made individual requests for tailored services for people with Down Syndrome and/or sensory impairments and/or Autism.

When thinking about what family members needed from daytime support - *lots of families wanted the peace of mind in knowing that their son or daughter was well supported and

'To have some time to myself'

safe. Within this context they talked about the need for reliable services - delivered by skilled staff. *Some people talked about getting the balance right for the person and the wider family and needing to be able to live their lives

and to hold down jobs. Some families presented this in terms of 'respite' from their caring role.

63% of families of adults said that the day services offer what their family member needs very well or well. 24% said they offered what was needed a little bit or not at all. 52% of the families of adults thought that the day services met their needs as a family well or very well.

We asked the families of young people how well informed they felt about the daytime support that might be on offer to their son or daughter in the future.

5.5% of the families of young people felt really well informed, well informed or quite well informed. 66.5% said they were not informed at all.

When we asked if families had anything else to tell us additional issues raised there was a



polarised response with *some families very happy with the (back to normal post Covid 19) status quo and *some very unhappy with the current offer. *Some families of a young person talked about a fear of the future. *Some people mentioned poor communication and

information from the Council. *Some people mentioned cuts and linked reduction in services funded or offered by the council *One or two people mentioned staff employed in day services, their career prospects, training and skills and ability to communicate well in English. *One or two people shared negative feedback about Direct Payments processes and a wish for more flexible, creative approach to technology. *One person was concerned about a lack of focus on the needs of people who use a wheelchair.

'I feel rather afraid for the future at present because after college I feel like there's nothing else, and I don't really know where to get information'

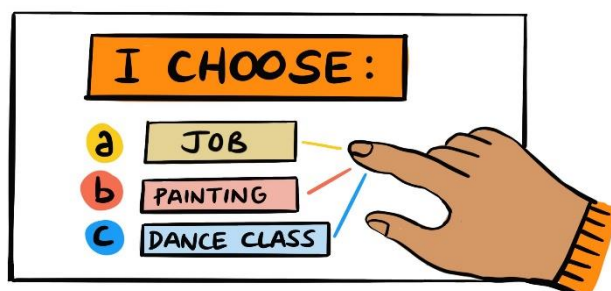
Professionals and advisers

Responses came from 50 people - representing 81 professionals who support or advise people and/or families. 33 of respondents were council employers, 6 work for education organisations, 3 were employed by the local health trust or CCG and 3 from VSCE organisations. Responses came from people in a wide range of roles including



When asked what could be changed to make day support better
 *lots of people talked about the funding and/or resources needed to do things like increase staff ratios, invest in equipment or more flexible timings. *Some people talked about funding for the skills and training of staff. *Some people talked

'The important thing is people want to feel useful'



about the specific needs of young people, of autistic people and/or those who are not eligible for social care services. Ideas like hubs and drop in sessions were suggested as were those linked to the more creative use of personal budgets and direct payments. *Lots of people

talked about having a strong focus on purpose with employment - volunteering and a stronger focus on aspirational life pathways seen as ways to achieve this.

A question about gaps in services and supports generated many responses that mirrored suggestions above. *Some people felt that the current system was not joined up around a person and their families and that this is not a good use of limited resources. There was a strong focus on young people and the 'cliff edge' at transition, autistic people, those with Asperger's and those who are not eligible for services. In addition, people who might challenge services were seen as a group facing gaps in support. *Some people also talked about people with Autism or ADHD who have other

'Many carers report to me that there are no relevant services for their family member with high function Autism and mild learning disability. That they remain home with no activities and no services that meets their specific need. Particularly, if there is an additional mental health need'

issues such as drug or mental health problems.

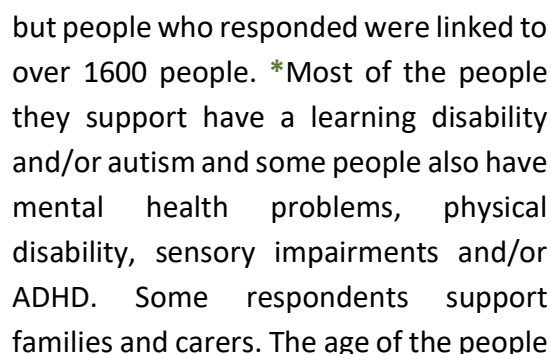
'Flexibility with the Direct Payments service, having more services to enable young people to have more social inclusion to prevent isolation in their homes'

More creative use of Direct Payments, including the potential for pooled budgets was mentioned by *some people as were gaps in support to help people socialise and date. Support to help people work and volunteer was seen as lacking by *some people. People spoke generally about a

need for a connected and integrated approach - that offers more variety and flexibility.

Responses came from 24 people. The majority worked within day centre settings, many for the council but also with good representation from the VCSE sector. There was a good mix of larger and medium sized organisations. Smaller providers were less well represented.

It was impossible to factor for double counting from people working within the same services



When asked about the key values that drive their service -*lots of providers talked about being inclusive and enriching people's lives. *Lots also talked about people enjoying themselves, engaging in activities and having fun. * Lots mentioned helping people to achieve goals, learn skills, achieve outcomes and become more independent and confident and to have a purpose.

'There needs to be various different services for all with learning disabilities within Merton. Not one service can fit all needs'

When asked about the impact of the Covid 19 pandemic on the services and supports they offer *lots of people talked about services and people being massively impacted with centres closing, reduced numbers and smaller groups. Some mentioned the need to be creative

and flexible with examples given of delivering support from a distance using the phone, internet or using outreach approaches. *Lots of respondents also talked about how hard all this was for the people they support and their families with many people not being able to comprehend the changes and of people who are distressed, isolated and vulnerable. *One or two people talked about managing the risks and of the resource implications of being providers and dealing with all the challenges of the pandemic.

'We are running two services on the same amount of money as before which is taking its toll'

91% of day service providers think their service helps people use what they are good at. 88% think their service offer is attractive or very attractive to new people and their families, including younger people.



When asked what could make their service more attractive to new and different people - *lots of respondents talked about the need for more resources, staff, funding, sessions and equipment. People also mentioned having more interesting and diverse activities and more time to

support people on a one to one and/or outreach basis. *Some people said that offering services on an evening and at weekends would be a good idea. *Some talked about services being better connected with their wider community through things like strengthened links, open days, visits, using community facilities and sharing their facilities. Social media was mentioned by *one or

'Hosting events in the community to bring awareness of what we offer'

two people as a way to better connect. A question about gaps in services and supports generated many responses that mirrored the suggestions above. *Some people took the



opportunity to say how much people value the existing day centres and outreach services and how Merton was more fortunate than other boroughs. *Some people placed a focus on young people and autistic people and gaps in support to help people socialise. Support for families - especially with the post Covid context was mentioned by *one or two people as was support for people to go on holiday or take breaks.

When asked about the barrier they face to doing things differently or better -*lots of people talked about funding and resources -

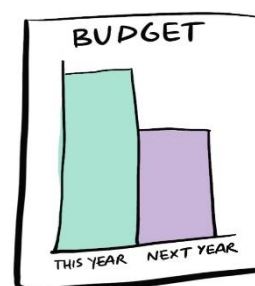
'Before the pandemic we had no barriers. If we thought of exciting opportunities for our customers, we would make them happen'

particularly those linked to staffing levels and staff training. *One person mentioned the need for space to expand

their offer. *One or two people mentioned the need for outreach and interpreter services.

*Some people talked about wanting to get

back to normal and *one or two mentioned the positive partnerships forged through the pandemic and the ongoing value of these.



Providers of services to people who get support during the day

Responses came from 15 providers of services run by both the public and Voluntary, Community and Social Enterprise (VCSE) sectors. Most offered supported living services, 3 represented care homes and 3 were VCSE providers who offered more community based support.

66% of the people surveyed offered services only in Merton

Between them they support over 100 people who use day services. *All the people they support have a learning disability and/or autism and some people also have mental health challenges and/or physical disability. People supported have an age range from teens to 65 - with the majority being people 18+.

75% of the people they support attend council run day centres. Other people attend college or get the help they need from VCSE organisations or from community organisations.

When asked about the key values that drive their service - *lots of the providers talked about helping people be more independent. *Lots also talked about helping people to achieve goals, live full lives, gain confidence, achieve dreams, master new skills and 'access the community'.

Thinking about daytime support - what is important to the people you support?



When asked about current approaches to day services, 73% think that current day services complement the support they offer well or very well.

'We don't speak frequently - so people we support mutually are possibly very different at home and at their day services. We may learn a lot about how to enhance our own service if we communicated more'

Joint working and poor communication between day services and other support providers were cited as key challenges by *one or two people.

When asked about gaps in services and supports in Merton *some people cited cutbacks and/or a lack of money and resources. *Some people said

there was a need for supports targeted at young people especially those who need less help. A lack of specialist support for autistic people was mentioned by *some people. Others mentioned wanting simple social groups and supported days out.

'Sports facilities seem to be lacking also specific spaces for young people that are influenced by hip hop and street style such as graffiti, DJing and street dance. If there was a facility like that it would open up so much...'

*Some people (3) added a thank you to day centres and mentioned their importance and value.

7. Diverse contributions

To make sure we were hearing from lots of different people we asked people with personal experience of daytime support and their families, to tell us a bit about themselves.

Location

99% of the adults and 96% of the young people lived in Merton.

90% of the families of adults and 100% of the families of young people lived in Merton.

Gender and sex

There was an almost 50/50 gender split between male and female young people with 4% identifying as non-binary. Adults 62% identified as male and 37% female.

The families and carers of young people contributors were 11% male and 89% female. The families and carers of adults were 35% male and 65% female.



Age

63.5% of young people were under 18 and 36.5% between 19 and 25. 43% of adults were under 39, 51% between 40 and 70 and 6% over 70.

14% of families of adults were under 39, 63.5% were between 40 and 69 and 22.5% over 70. 11% of families of young people were under 39 and 89% between 40 and 70.

Ethnicity

Just over 45.5% of the young people identified as White British, English or White. 6.5% were White European, White Irish or Albanian. 6.5% were mixed race or heritage. 26% were

Black, Black British, Black African, British Caribbean or Black African. 13% were Asian, British Asian or Sri Lankan. Just over 2% declined to answer.

Some of the adults spoke to us as part of a group and their ethnicity was not recorded. Of the remaining adults who answered the question 70.5% identified as White British, English or White. 6.5% said they were White European or stated a named EU Country. 13% were Ghanaian British, Black British, Afro-Caribbean, African or Jamaican British. 9% were British Asian or Pakistani, Asian, Sri Lankan or Hindu. 1% stated mixed race.



76% of the families of young people identified as White British, British, UK, London, English or White. 12% were Black British and 12% British Asian or Pakistani.

66% of the families of adults identified as White British, English or White with 6% White Other. 15% identified as British Asian/Pakistani, Pakistani, Indian or Mixed Asian. 11% identified as Afro-Caribbean, Black African, African or Jamaican. 2% Sri Lankan Tamil.

8. Notes

Covid has had an impact on people and the support they get/want during the day. Some people seemed to find it hard to share their aspirations for the future within this context.

Many people with personal experience were supported by day service and education staff to complete a survey and/or engage in a conversation. This may have influenced how they responded to some of the questions about day services/education and their staff.

Some people filled in a survey that may not have been designed for them. From the data supplied it is impossible to determine which stakeholder group they are actually in. Their responses have been included in the stakeholder category in which they submitted their data.

The system appears to have generated a very small number of repeated entries but only for some questions. This appears to be less than 10 in total. We were reluctant to delete whole submission in case they are not repeats. We have not included obvious repeats in word cloud weighting.

Not every person answered every question or did not supply a relevant answer. This is particularly the case where submissions were from groups. Percentages are indicative rather than definitive and will be more or less accurate depending on the number of people who answered the question. Many people gave more than one answer to many questions. We have tried to record these entries fairly. Percentages have been rounded up or down.

Word clouds have been developed giving weight to the number of times something was mentioned. The larger the words - the more they or similar related words have been mentioned.

Thank you

A huge thank you to everyone who joined the Reference Group, engaged in the Big Conversation or helped in any way. Your support and hard work is really appreciated and we hope you feel this report does it justice.



