

My Daily Life, My Choice

Co-produced Review of Day Opportunities:

Report of the Empowering People Team and RedQuadrant

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Contents

Review summary	3
Background and purpose	5
Brief for the review	6
Evaluation of the training and support element of the project.....	7
Engagement events and work of Empowering People Team	12
The questions for the engagement events	13
Day opportunities and the pandemic	14
What people want from day opportunities	21
What helps you do the things you want to do? What gets in the way?.....	29
The voice of future day opportunity users.....	38
The next steps	41

Review summary

Birmingham City Council commissioned RedQuadrant to deliver a co-produced review of day opportunities in the city. They wanted to engage a wide range of people involved in day services – the people who use them, families, carers, providers and other professionals. They wanted to understand the impact of the pandemic on people and services and wanted to hear what people valued about day opportunities and importantly how they can change for the future. This report will provide the foundation for the next steps in planning for day opportunities in Birmingham.

An essential part of this work was the recruitment and training of people with lived experience, bringing them together as a group to lead a programme of engagement sessions where people could give their views. Fourteen people with lived experience were trained and worked with RedQuadrant consultants and the commissioning teams to deliver 35 in person and online engagement events attended by over 400 people.

The findings from the review are set out in detail in this report. Where possible this is presented in the voice of the people attending the events. The Empowering People Team (EPT) met on the 18th January to reflect on the training they received and the main findings as they saw them. Their feedback and views are included in this summary and throughout the report.

The impact of the pandemic

The closing of day opportunities during the pandemic had a major impact on people using services and their carers. It was also a very difficult time for staff and other professionals involved. Initially there was a lot of worry, confusion and there was a sense of crisis.

Providers and the council came together to find new ways of supporting people and their families. People across the engagement sessions spoke with pride at the way staff, the council, commissioners and families supported each other providing zoom sessions, meals, activity packs and garden visits.

The impact of the pandemic has been detrimental to people's health and wellbeing, exacting a cost on people who use services and their carers with many reporting a decline in physical, mental and emotional wellbeing. That impact is still being felt and for providers many were finding it difficult to return to pre pandemic levels of service.

The importance and status of day opportunities

People using day opportunities spoke passionately about how much they valued the support they received through day opportunities. It is their community, it is where they meet friends to do the things they enjoy with other people.

Carers saw day opportunities as essential in enabling them to have a quality of life outside of caring. It allowed them to do the things they needed to do in maintaining their own health and wellbeing, and to do the everyday tasks necessary for themselves and their families.

A theme across the engagement events was a lack of understanding of the benefits of day opportunities in the wider community. As well as being places where people met their community and friends they are 'hubs' in which people get a range of care, health and other support. People wanted personalised support with high levels of training in a wide range of communication, support and care skills.

The barriers people faced

The importance of transport in enabling people to take part in day opportunities was a key issue. The review highlighted the problems that people currently experience on a day-to-day basis and the EPT felt there was a need for providers of transport (public and specialist transport) to understand the impact it has when it doesn't work well.

People wanted to engage with wider community activities more but felt there are numerous barriers to them doing this, including lack of facilities like changing places, the accessibility of venues, spaces and buildings and the attitudes and understanding of the public and staff in mainstream services.

As a consequence, many were often anxious about engaging in wider community activity on their own and even in groups many felt they were not welcome in places like shops, leisure centres, restaurants and places of entertainment.

There were some views that the facilities, activities and level of staffing and training were not the same across day opportunities. For example, some older people felt they didn't get the same access to activities as young adults and the range and standards of provision for young people with complex disabilities in specialist schools and colleges were not as widely available in adult services.

Many carers felt that they had to fight to get the services that were essential to enable them to undertake their caring roles. They valued the access to services they had gained and wanted continuity and certainty, which they felt was threatened by the assessment and review processes they faced. Providers were also concerned about the access to social work assessment, review and referrals. This led to delays and uncertainty for families as well as for services in planning and making continuity of care difficult to achieve.

The importance of everyone working collaboratively to achieve outcomes for people

The review findings highlighted examples of joint working and opportunities for day services, specialist schools and colleges and health and care professionals to work more closely together. The EPT members and providers involved in supporting them in this review also felt this collaborative, co-productive approach was essential if the findings identified in the review are to be addressed. They wanted to continue to be involved in taking this work forward together with the council and providers.

The work the council is proposing to take forward in developing a co-produced strategy for day opportunities was welcomed by those involved in the review. The EPT were keen that the learning is actioned through the development of the strategy and should also inform work that is taking place in the strategies for preparation and transition to adulthood, carers and respite.

The commitment shown and the partnership working from the commissioning and preparation for adulthood teams and providers was greatly appreciated by RedQuadrant and the EPT. This was crucial to the success in enabling the voice of people to be heard and in supporting the delivery of a genuinely co-produced and independent review.

Background and purpose

As part of Birmingham City Council's ambition to realise its vision, they are committed to planning with people and partners, to make the most effective use of local resources and develop solutions to continuously deliver high-quality person-centred care. In December 2021 a report was presented to Cabinet which provided an update on the progress with the re-opening of building-based day opportunities services for the citizens of Birmingham after a significant period of closure due to the pandemic. The report proposed that a co-produced review of day opportunities services is undertaken in the light of the pandemic to understand any lasting impact.

The day opportunities within the scope of the review support adults with learning disabilities and autism, physical disabilities and older adults including those who have dementia. The review focuses primarily on day opportunities supporting those who are eligible for support from adult social care and the Transitions and Preparation for Adulthood Service. Currently the council's internal day service supports younger adults (18-65yrs) across nine sites including four gardening projects. There are also 45 third sector and private organisations providing day opportunities services in Birmingham or near to Birmingham. They support adults with a range of support needs including learning and physical disabilities and older adults with dementia. These organisations are funded either directly from social care, direct payments, through self-funded placements and in some instances through grants.

Brief for the review

Birmingham City Council commissioned an independent co-produced review of day opportunities in the city. RedQuadrant was appointed to develop and deliver the review in partnership with people who use services, carers, service providers and other stakeholders. The review included learning over the last two years in light of the pandemic. It aims to capture people's experience, views and ideas – what's worked well, what hasn't worked well, what new ways of working that have proved valuable and what people have missed over this period. Importantly it asks about people's aspirations for themselves and how they feel day opportunities could support them in the future. The review also heard from their families and carers and other stakeholders including the services themselves. The lived experience of people who use these services was central to both developing and delivering this review. The first stage of the work was to recruit and train a group of co-producers to design and deliver the review sessions. Wherever possible we went to meet people in locations that are most familiar and comfortable for them and we will also include options for people who prefer to meet online or are still isolating.

Evaluation of the training and support element of the project

Approach and methodology

The purpose of this element of the project was the recruitment and training of co-production participants.

The project outline from BCC asked RedQuadrant to:

- To recruit a group of volunteers to the co-production programme from amongst those who use services, carers, and other stakeholders.
- To co-ordinate and lead on the delivery of a short training programme (circa 4 sessions) for the volunteer participants to be delivered in response to level of interest, accessibility and capacity.

Volunteers were recruited by from day opportunities. All centres were asked, and people came forward from Moseley Day Centre, Cerebral Palsy Midlands (CPM), Sutton Support, Heartlands, the Preparation for Adulthood Team, Carers and from the wider community. In total fourteen people volunteered and those with greater support needs were accompanied by workers from their centres. Thirteen people completed the training and co-produced the delivery of the review. These people were split into two groups to enable those with greater communication or support needs to have the opportunity to work at a pace which suited them.

Both groups undertook the same four session training programme which covered the following topics

Session 1 – What is co-production?

- Introduction and ground rules
- Getting to know each other.
- What is co-production and why do we need it?
- A co-producer's role

Session 2 - Your story and how to use it.

- Working out what your story is
- How to draw out the lessons from it for others
- Talking about feelings
- Practising telling my story

Session 3 - Co-production is about talking to each other.

- What is important about how I talk to others?
- Dealing with positive and negative responses

- Building confidence
- What should I expect, before during and after a meeting or event?
- What do we need to do the job well?

Session 4 Beginning the Journey

- Recap on what we have learned so far
- Introducing Paul Kelly (RedQuadrant) colleague leading on the review report
- Our first piece of co-production – co-development of the review activities and questions

These sessions were designed and delivered by Lynda Tarpey (RedQuadrant) working with a Birmingham resident with lived experience of services to co-produce the sessions and were flexed to the needs of the participants once they began. For example, one of the 2 groups asked for the Birmingham City Council commissioning lead for this work to produce a presentation about the decision-making processes of the council so they better understood the context of this work.

Listening to Participants

At the end of the four sessions participants completed a simple evaluation form thinking back to when they started the training and how they felt at the end of the sessions. This asked them four yes or no questions.

- Do you feel more confident about volunteering to help Birmingham City Council?
- Do you feel more confident to talk about your experience of services?
- Do you feel more confident to talk to other people about their experience of services?
- Do you know what is meant by co-production?

Everyone responded 'yes' to all questions other than one person with a learning disability who responded 'no' to the last question

Additional comments made at that point were:

- 'I found it interesting'
- 'The first meeting we were unsure of what the expectations were but now I know'
- 'I have enjoyed the chats and getting to know each other'
- 'I would like to be in more projects in the coming days. It has boosted my confidence'
- 'Amazing'
- 'It has been a very good training program this last few weeks'

At the end of the training sessions participants requested extra time as one whole group to practise for the next phase of the work when they would be going out to talk to others about their experiences. This was arranged for them along with prompt sheets for the questions they would be asking people.

After all the engagement events were complete the group of co-producers came back together with RedQuadrant and commissioning colleagues to both think about their overall experience of this work and to check that the messages Paul Kelly (RedQuadrant report author) was going to write in the final report were consistent with what the participating individuals had heard and were supported by them.

Below are the reflections from participants on their experience at the end of the engagement activity

Prior to joining

People observed that at the beginning they were not really sure what they were signing up for. Two volunteers dropped out as they did not feel it was for them.

Quote from a centre manager

‘I was sceptical at the beginning but the experience has made me reflect on how we do things in our centre ‘

Experience of the training sessions:

- Good to practise communicating in all group sizes
- Printed PowerPoints helped stay on task
- Built confidence and self-esteem
- Feeding back to others at our centre was good
- Biggest problem was transport both timing and reliability
- Everyone coming together (from both groups) in the last session was good
- Everyone had an opportunity to speak
- More confident to lead a meeting and speak
- I felt informed
- You learned to speak up for yourself
- I realised my voice matters
- The broad range of organisations involved was a strength

Quotes from participants

‘The training was so good. It gave me confidence to do this and lots of other things as well.’

‘I used to just say things and sometimes that didn’t turn out as I wanted. Doing this has made me think about what I say and how I say it, so people listen to me more.’

‘I felt worthwhile doing this.’

‘We were treated as equals.’

‘Training has helped build confidence – went miles better than expected.’

Experience of leading the engagement sessions

- Encouraged to help others
- Eager to do more
- Having questions but us being able to change them as we went along worked well
- Day Centres were well attended
- Gave me an opportunity to use my skills
- Disappointed social workers did not engage
- One event felt like too many people attended
- Learning lessons from others worked well
- We want to see what will change (LD can we see even small wins)
- People need to be clear about the objectives to participate
- Needed more information to share with DCs to encourage people to attend

Things that could have been done differently

- Lack of accessible toilets, changing places, hoists at some venues was a problem
- Pre-booked taxis created stress not turning up or at the wrong time
- Some found being videoed difficult
- Having all the information on day one
- Not everyone was able to comment at the colleges due to big numbers

Reflections overall

- It went well – glad we had the training
- Training engendered confidence helped with speaking up
- Participants liked the questions they were asking
- Meeting new people was good

- Grown in confidence- become a team
- We had good information to lead sessions with
- Two groups coming together was good but glad we had some time separate first
- I was encouraged to help others
- Eager to do more having done this
- Disappointed social workers did not engage in the sessions for professionals

Quotes from participants

‘Don’t let this be a tick box exercise after all our work’

‘We (Carers) need to be positive and not just focus on the negatives’

‘We want to know what happens next – keep talking to us!’

Summary

In terms of the participants, they were all in agreement that being part of this project to date had been an enjoyable and interesting experience which built their confidence and self-esteem. The participants with lived experience were also clear that the training element had been fundamental to achieving this.

All participants were keen to remain part of this and other co-production activities with the caveat that they want to see change as a result. They were realistic that sometimes these may be small. However, they were clear that from their perspective part of a co-productive approach was that Birmingham City Council will keep them informed about the next steps in work they have been part of. They agreed that this would be what will keep them engaged and confident they are not being used as part of a tick box exercise.

The two areas which participants found particularly difficult and which stopped them participating at times mirrored what was said at events during the review as general barriers to daily life. These were:

- Transport – timing and reliability
- Lack of accessible toilets, changing places, hoists

Engagement events and work of Empowering People Team

Working with commissioners and providers we recruited 14 people with lived experience of day opportunity services in Birmingham to be trained as “co-producers” – They named themselves “the Empowering People Team”. RedQuadrant worked with 14 members of the EPT to develop the “engagement questions” that would be used to enable people to give their views into the review.

A programme of engagement events was developed in partnership with the commissioning team and providers – it was important that this programme was inclusive and comprehensive giving anyone involved in day opportunities in Birmingham the chance to have their say. This included days services for people with learning disabilities, cerebral palsy, older people, people with multiple and complex disabilities, people with physical disabilities and acquired brain injury.

In total 35 engagement events were held to bring people together to give their view including specialist services for people from the Caribbean, Chinese and Asian communities were visited. The majority of these were led by members of the EPT and RedQuadrant and all were facilitated by staff from adult social care commissioning team who organised venues, transport and took notes.

More than 25 day services and special colleges across Birmingham opened their doors to host these events enabling the people they support, carers and their staff to contribute to the review. The aim was to provide a variety for options for people to engage and where possible going to meet them in places that they felt comfortable and supported in addition to the 25 engagement events held at day opportunities and colleges others were in community locations including community centres, coffee shops, accessible venues and council offices. Three further events were offered online for those that couldn't make a face-to-face event or could only meet in the evening. A review open drop-in event was held – seven services and providers set up stalls and spoke about the services they provide to those that attended.

In total over 400 people attended events to give their views and hear from others. Over 250 of these were people who use adult day opportunities, attend special schools or colleges or are their informal carers and families. The others were staff enabling people to participate or providers and professionals working in the system.

The questions for the engagement events

The EPT worked with RedQuadrant to develop a set of engagement questions to guide the conversations they would have with people. These questions needed to draw out what was important to people and capture their experience of day opportunities. Given the wide range of groups and needs the questions needed to be adaptable to suit the people they were meeting, enabling them to understand and respond. These were put into accessible formats and copies were made available by the Commissioning team at each event. We would like to thank the carers and staff from day services supporting EPT members. The skills, time and experience they brought were invaluable in enabling people to participate.

The core set of questions that were used at every event for people who used services were:

Day opportunities and the pandemic

- What worked well?
- What hasn't worked well?
- What did people miss most?

Looking to the future

- What's important to you?
- What do you enjoy doing?
- What would you like to do that you don't do now?

What helps you do the things you want to do? What gets in the way?

We would like to also thank the staff from day services who enabled the people they support to participate. They used the skills and knowledge they have about the people we were meeting with to enable the EPT and RedQuadrant to engage with them in a way that made sense to them and in locations that they felt comfortable.

These core questions were also adapted for the events with carers, providers and for the schools and colleges. In addition, a set of shorter questions were agreed with the EPT, designed to encourage people who are non-verbal or who find it difficult to communicate to have their say.

The feedback from the events is presented below under the three key headings developed by the EPT.

Day opportunities and the pandemic

We asked people how they felt during the two years of lockdown and other restrictions. Across all the events it was clear it was a very difficult time for people and the impact was still being felt. Many people using services said they felt upset, scared and lonely. Boredom was also a feeling expressed by those who didn't have activities to do and day centres to attend. During the pandemic people said that they felt

- Frightened
- Bored
- Depressed
- Confused
- Anxious
- Stressed

'I was anxious, no (regular) places to go - I also had problems with supported living accommodation during lockdown'

'I was scared, didn't know what was happening'

'It felt like a real crisis - both in terms of having to deal with crises and understanding that we were in a crisis situation'

We asked what they missed most. Overwhelmingly the response most people gave was that they missed meeting friends and staff. They missed having things to do and also spoke of missing having someone to help them in getting the support they need.

Carers and providers said that people's physical health also worsened with declines in mobility, energy, skills and confidence. They reported significant and noticeable changes in health, wellbeing and the behaviours of the people they cared for. The symptoms of conditions worsened:

- Anxiety
- Depression
- Frustration
- Anger
- Lost skills and mobility

It took time for services in health and care to develop their response to the pandemic and whilst this was happening carers felt isolated at a time when normal support systems were

no longer there and they themselves were needing more support to do the day-to-day things necessary to keep families together and well.

‘Over lockdown it was noticeable that she was getting worse without the usual stimulation.

‘Since Covid she has found it difficult to go out’

‘She’s developed oedema in the legs which makes activity even more difficult as he is quite slow moving and I can’t push a (wheel) chair’

‘As a carer I need a break and if staff hadn’t kept in touch during COVID, I don’t know what I would have done. Telephone lines were and are permanently busy in social services’

For Carers this was a worrying and challenging for them. The suddenness of the national situation and the consequences for services meant that they were left feeling anxious and alone and there was enormous uncertainty over the things that are important on a day-to-day basis.

‘My husband has severe dementia and it was awful during Covid we were stuck at home with little or no respite from each other - all he wanted to do was go out but couldn’t’

‘People were struggling, there was a general feeling of ‘helplessness’ and almost despair from carers’

‘The effect of the pandemic on some people is they have even attempted self-harm due to frustration’

There was a variety of responses from day opportunities to help people. At the events people spoke positively about the creative ways in which services responded to support people who use services and their carers. Keeping people connected online was one of the first responses. Zoom meeting and quizzes brought people together.

‘My wife is disabled and I have health problems – the service was brilliant phoning every week and coming out every few weeks to bring packages’

‘Zoom calls kept us involved and telephone calls helped us keep contact with the centre so that if we needed help, we knew who to ask’

‘Felt depressed during lockdown, really stressed and upset did manage to see some friends in online meetings but missed seeing others’

Despite these efforts many carers and people using services found it difficult to cope. Not everyone was able to connect online. Not having the equipment or broadband was an issue for some we spoke to and services reported that many don't have the skills or knowledge to access information, support and activities online. Staff checking in and keeping touch by phone was described as a lifeline by some.

'Online was not for everyone. We spent time making sure people could get connected'

'The online calls (zoom/teams etc.) worked well but had the problem that not all individuals have the same technical knowledge or equipment at home which would enable this to work well or to its best ability'

'Often the older members of the population have limited experience with devices and how to work them and so prefer to meet with others physically in order to share information'

'The lockdown and closure of the centre didn't work for me even though the centre provided things to do I still missed being with other people'

As time went on new and creative ways of supporting people were developed. People were sent activity packs for art, knitting and other activities where people met together online to complete. Staff in some centres also organised garden and driveway visits that were popular and appreciated bringing face to face contact to people where they live. Some centres took lunches out to people and were there to provide advice and guidance through a very uncertain time. Staff at some centres were there to provide phone and online support and helped people connect to other welfare and health services.

"We made DVDs for those who didn't have IT – fitness and crafts"

"People came twice per week to bring me a meal, it was good seeing people in person"

'My dad attends the day centre, they gave us video's exercise, hints and tips we need a day centre such as fairway'

'During lockdown the day centre was brilliant – activity packs, frequent phone calls, offers of support, dedicated phone line'

'We were able to meet up with some people at their homes during the lockdown this helped reassure them that they were not alone and isolated it also provided a kind of 'sitting service' to enable carers to be able to do the things that they needed to be done without worrying so much about their loved ones'

‘The people at the centre (staff), helped me during covid especially when I lost 5 members of my family in 2 weeks and I needed a lot of support’

Most centres reported that they were still in the process of getting back to normal. Some were still not undertaking the same range of activities. Trips out to the community were restricted because of concerns over keeping people safe (staff and service users) and due to unavailability of staff. Some were still practicing some level of social distancing.

People using services reported that they were still anxious about covid due to clinical vulnerability but also having lost confidence in travelling, meeting other people and participating in activities. Gains that had been made in confidence and social skills had been lost for some.

The frustrations and worries of service users and carers was also reflected by providers. The risk and uncertainty brought by the pandemic was unprecedented and they found it challenging to change in response to national requirements, client needs and safety for staff. The Council required day centres to close their doors but they were acutely aware of the need and impact for the people they support.

‘We haven’t got computers anymore. (Staff member said that they have computers and used to have a computer room but they haven’t set it up again since Covid)’

‘Activities that were on before Covid have not started up again’

‘We are their normal and it was lost. Scary going back to normality’

‘The loss of regular routines and not being able to do the activities that maintain health and wellbeing has impacted both on people using the services and also for carers’

‘We have seen increase in worse health issues. We had to ‘challenge’ some carers to help keep them going. Had to support families with language barriers to access other support’

‘My wife was walking before lockdown but not now’

Liaison with the council and health was essential and all reported how difficult it was to navigate through national and local guidance as well as challenges with PPE and arrangements for remote working. New ways of working emerged and plans put in place to find ways to support people whilst keeping with regulations and keeping people safe. Providers valued the support of other services whilst recognising just how difficult this time was:

‘The pandemic really affected staff. Caring for carers as well as service users – home visits, telephone, facetime. We realised how important day centres are. Activity packs were appreciated’

‘Support of council over covid was superb’

‘Worked well with known health colleagues’

Across providers there was a concern about the impact that covid has had on the people and families they work with. Providers spoke with pride about how they managed to creatively find new ways to support people and families. Some reflected on what they saw as the central importance of day services in people’s lives not just in terms of meaningful activity but also in providing community for people with friendship, a sense of purpose and belonging as well as peer support. They also highlighted the role as a focal point for connections between people and families and the range of support and services in the community.

At many of the events there was reference to there still being some people who expressed concern about returning to centres, not just those who are clinically vulnerable. For those that have returned staff are noticing changes across a range of issues including declines in mobility, daily living and social skills as well as emotional, mental and physical wellbeing. For some this has meant they feel they are now dealing with people with higher levels of needs.

‘We are seeing increase in dementia – 80% of service users have dementia. As disease progresses and needs become more complex 1:1 support is needed and we don’t currently have the funding or staff numbers to manage this’

‘Our service users became more dependent due to lockdown and this has caused extra strain on carers and families’

‘They have come back different – changed them. They had to get to know us again’

‘Some service users have become more confused since the pandemic and they didn’t understand why they could not go to the centre’

‘It is difficult to get people come to the centre as they have lost confidence especially the older people’

Carers and providers spoke about changes to the wider health system and how this was impacting on people going to centres where they had health conditions.

‘Over the covid period the limited services provided by health have had an effect on the health and wellbeing of individuals’

‘It would be better if there were more services available at the centre such as health services including physiotherapy, or the availability of medical services as often it is difficult for carers to take citizens to appointments during the day if they have other responsibilities’

‘The care provided by the health services since the pandemic seems somehow less (forthcoming?) than it was prior to 2020’

Providers reported that the pandemic has had an impact on their services and their ability to return to previous levels of service. Some reported that attendance has declined and this has impacted on income. Some also said that expenditure has increased with transport costs increasing and the availability of free or low-cost activities having increased.

Staffing is a major issue with recruitment and retention a challenge for many services:

‘Used to have more service users before Covid – starting to get back to normal’

‘Drop in referrals from social care – leads to lack of funding’

‘With reduced funding due to attendance, it is becoming difficult to continue to provide the range of activities that were provided prior to the Lockdown’

‘The number of staff available is still limited as some staff left and it is difficult to recruit more at the moment’

People using day opportunities rely heavily on accessible transport and many providers felt that this is an area that had got worse since the pandemic

‘Since covid most private transport providers have no capacity’

‘Now using a taxi company and subsidising cost of longer journeys’

‘Since covid, service users anxious about buses etc’

For some services they have examined their approach to the model of delivery to see how they can be more personalised and thinking about how they can enable people to access the community.

‘Covid gave us time to plan for a new PA style model – including individual plans and travel training’

What people want from day opportunities

When the EPT met with people they asked what was important to them in their lives, what people like most about the day opportunities they went to, what they enjoy doing most, what helps them relax and what ambitions they had for the future. They tailored the questions to suit the audience changing the wording for carers and for provider discussions.

What was important to them?

- Family
- Friends
- Doing things I enjoy
- Relaxing and having fun
- Working – a job or volunteering
- Helping others

What did people enjoy doing?

- Meeting friends and family
- Arts, crafts, knitting, playing music and cooking
- Quizzes, playing games, computer games, watching films and TV
- Gardening, outdoor exercise and playing sports

The lists above show only a small proportion of the activities and benefits that people valued. The list would be endless and there were still many more things that people said they would like to do or do more of. Providers also had views on what they felt day opportunities provide for people attending them, around promoting independence and important time away from families

‘To get better at reading, writing and using numbers’

‘Help more in the kitchen and to cook’

‘Gardening and green fingers project – a gardening project run by the centre helps with coordination, stimulation and calming’

‘They also allow people time to express themselves away from their carers and for the staff to highlight any potential safeguarding concerns’

‘It’s the little things that matter. We did a fundraising event in a park on a Sunday. This meant a lot to our service users who took part as they don’t normally get to go out and socialise on a Sunday’

Some spoke of activities that they would like to bring back...

‘Like to go back to the evening club (dance/social club)’

‘Help to go to Work – the centre used to provide work activities for attendees to participate in, this is difficult due to staffing levels’

This variety and choice was important but it was also important that they have certainty and are able to do things they enjoy on a regular basis. People using services, carers and providers all spoke of the importance of routine and continuity and spoke of the disruption to lives that can occur when things are changed or cancelled.

Day centres were seen as places where people felt safe and welcomed. They valued the community and friendship they experienced when they went to the centres. People also spoke about day opportunities enabling connection with the wider “community” and other services.

Some of the groups of people the EPT met at centres for people with learning disabilities found it difficult to answer questions about the future. Instead, they asked ‘what else would you like to do that you don’t do now?’:

- Trips out into the community
- Visits to restaurants and pubs
- Holidays

At the centres for physical disability the people attending really valued the opportunity to meet with people who were facing the same challenges they faced and valued the support of the staff.

‘I would like to gain confidence to go out and be enabled to go out and to cope with my disability, I was really angry after my accident but with the help of the centre I realise that it is ‘all right to ask for help,’ and I have realised that there are that there are a lot of other things that I can do that I didn’t think I could do. It helps with me accepting my anger over my disability I do find that the centre also helps my family by giving them a break so that they can do what they need to do for themselves’

When asked what else they wanted to do in the lives there was a lot of enthusiasm for getting out of the centre into the wider community.

‘I like to go out with the centre, sensory walks, pub meals, just wish things were more like they were’

‘I would like to go to college and also would like to do Wheelchair rock climbing!’

‘I would like to do more sport and exercise, sports, football, blind cricket’

At the centres for older people, they valued meeting others and being with friends. The impact of covid was still being felt.

‘I would like to be able to do more activities, but this is difficult as there are only a few rooms open’

‘Being warm in the winter and being with friends’

‘I’d like to be able to show others how to do things, like teach younger people how to knit’

‘The council got me physiotherapy and speech therapy – I want to attend more often’

‘Like to get back more to how it was, we can’t have a Christmas party with entertainment due to risk of covid infection’

‘Like to do more activities such as swimming etc. and an enablement programme to help me do more things’

Some of the younger people with disabilities expressed ambitions and aspirations and wanted to be:

‘Set for the future and having a plan – showing others what you can do’

Others also were worried about the future ‘life without my family’ and what that would mean for them. Similarly, families know they have to prepare for the future when they may no longer be there or able to look after the person they care for.

For carers day opportunities were essential to their own wellbeing and health, and that of their families. For some it was an important place that they could go to for advice and support about a wide range of issues relating to the person they cared for and themselves.

'Being able to afford things such as a carer when I'm not around or transport, I'm a self-funded person so things are even more difficult'

'The days, or time, when he's at the centre are very precious to me, they allow me to do the things I need to do which I couldn't normally as he cannot be left alone as it would be dangerous'

'Day opportunities provide a safe place where our loved ones can attend, this gives us time to be able to do the things we need to without having to worry about them'

'It gives me the time to do the things I want to do when I need to do them'

'They help you maintain at least a feeling of routine'

'At my day centre we have a 'friends of group' - it feels like a partnership with the service'

The carers on the EPT included a question about how it feels when the person they care for goes to a day opportunity:

- Give comfort
- Provides respite
- Gives piece of mind
- Provides a safe space
- Gives young people a chance to learn

'Makes me happy to see her happy'

'Helps plan for the future – I am getting older now and she needs support when I am gone'

'Gives me time to help support the wider cause!'

'Gives carers a few hours to reset and relax, enables them to do what they need to do or want to do, better able to cope'

'Day services are real lifeline for families, it is good to know that our loved ones are in a safe environment and are well cared for. This gives me a period of relief and time off from my caring role, a bit of time on my own to be able to do the things I need to or want to do'

‘My daughter feels vulnerable in unfamiliar places. At day centre she is safe with friends’

For some they were also places where they got to meet other carers sharing their experiences, supports others and gaining an understanding of what is a complex and changing systems of health and care.

‘We get little from social care, but we manage to ‘get by’ with what we can get’

‘Getting round a table chatting to each other is positive that make contribute to making things better. Doesn’t have to be commissioned’

Many of the carers at the events spoke about the impact of isolation, fear, anxiety and uncertainty and what felt like the relentlessness of caring day in day out struggling to “cope” and “get by”. For those caring for people with a variety of needs that included learning, mental and physical disability the complexity of the system they had to navigate on a day-to-day basis was enormous. This required day services, respite, health and transport to work together if care and support is to be effective. Without this, other aspects of the carers’ life were also impacted including their health and wellbeing.

‘You don’t realise how stressed out you have become until you have a period of respite while they are at the centre, otherwise you just keep on and keep on until you make yourself ill, then who will look after them?’

‘Day opportunities provide essential respite for carers – enables carers to rest (just to do normal housework and day to day things) rather than constant care’

‘My daughter is reliant on day services provided by a council run centre, as the residential care she lives in does not provide any stimulation, it has limited activities I am however involved in a group which provides fund raising to help fund activities and equipment which BCC does not provide. This could be rolled out for other centres’

‘I have some great support from as there is no respite available locally so rely on the centre. The experienced staff are good but the newer staff are inexperienced and need a better understanding of disabled people’

‘Could there be a pool of experienced staff (personal assistants) that carers could call upon?’

Many of the carers we spoke to spoke of the battle to get the support they and the person they cared for needed. This was also described as relentless and the worry and uncertainty brought about by changes to services, funding pressures for care packages and changing levels of need and circumstances. They greatly valued the services they had but many spoke of the struggle and battle to get them and then to hold onto them, making them work with a web of care that they felt they needed to protect and maintain.

‘Gives me a break and time to myself without it, it becomes difficult to care for X’

‘Let’s me have time to have a social life’

When looking to what can change for the better some providers reflected on the last two years and what it is day opportunities can do best:

‘Generally, day opportunities are good at helping users to do the things they would like to do in that many centres have an awareness of the opportunities available in their vicinity even if the activity is not provided by the centre’

‘It’s important to be outcomes focussed, person centre plans, targets to measure progress no matter how small’

‘Peer support from others with similar experiences and backgrounds. Man with Huntington’s who had never met anyone else with the same condition until he went to the day centre’

‘Rehabilitation from lockdown – regain skills for home and life’

‘Travel training, using IT’

‘don’t just look to the past – the future looks different and the world has changed’

Others spoke about the importance of person-centred outcomes for people who attend and the benefits they can bring in increasing independence and preventing or delaying the need for other health and care services:

‘We provide a person-centred approach talking to individuals and finding out what they want to achieve and help them progress towards those goals’

‘Working as a group can help to increase mobility skills’

'Being able to attend increases people's social interaction, gives them a feeling of purpose and responsibility'

'Giving individuals or groups a feeling of belonging and achieving something worthwhile'

'Keeping individuals more active and reducing dependence on others'

'Providing activities such as gardening - a decent fulfilling day'

'Prevention and rehabilitation'

'Day centres slow down entry into residential care'

The health and wellbeing of people was a major theme in the events. At the drop in event there was a great deal of discussion about the potential for learning disability day opportunities to play more of a role in enabling learning disability health checks to take place – the health team leading this in Birmingham were also keen to involve EPT as champions to support this work. Across all client group providers and professionals saw day opportunities as playing a vital role in helping people stay physically and mentally well:

'Ensure that an individual is getting a meal and enough to drink and they are not 'slipping' mentally and physically'

'Try to keep the individual stimulated and interested in things'

'Healthy eating, fitness, cooking, mental health support'

'We struggle to find fitness instructors who can support adults with physical disabilities'

'We have a memory café for people with Alzheimer's'

'The attendance of an individual at a centre can help stave off having to go into a residential or nursing home'

People who attended the events were very aware about the importance and benefits of day opportunities to carers. This was a major theme across all the sessions, not just those with carers.

‘Provide a type of respite for carers, allowing them to be able to go out and do the things that they need to do for their own well-being’

‘The day opportunity provision ‘takes some of the weight’ off carers in that they know their loved ones are in a safe place with people who will be able to look after them’

‘It gives the service user something to look forward to and can make them less frustrated’

‘There have been times when I just wanted to give up and take her to A&E for them to take over’

‘Day centre is open 50 weeks so valuable for carers and for citizens who don’t have family’

‘Provide a period of respite for families and carers so that they can have some semblance of a ‘life of their own’

‘As a parent trustee I advocate for others who are not getting the support they need...treat parents as experts, otherwise there will be unexpected consequences for carer and young person health and wellbeing’

Providers spoke of the support that they provide to families and carers. A number of providers had family liaison staff that can be there to support with a wide range of issues – some were people with lived experience of caring for people with disabilities and this was felt to be invaluable providing the experience and empathy that peer to peer support can deliver. One member of staff spoke of their ‘3 families – home, wider family and here’:

‘Some members of staff can provide access to advice and welfare services out of normal hours to help families cope with a crisis’

‘Staff can help with arranging appointments with services or organisations which wouldn’t necessarily be easy for a carer to do due to other commitments’

Providers spoke positively about the range of initiatives and ways of working that are targeted at Carers and supporting them and wider families in the caring role and in accessing the support and services they need.

- Mental health first aider
- Coffee mornings
- What's app group
- Open door policy
- 8.30 early bird club for working carers
- Staff often available out of hours for isolated carers
- Carers' support groups

What helps you do the things you want to do? What gets in the way?

The EPT asked people to say what helps when they want to do things in their lives. The type of support that helps them do the things they do at day centres and in the community. And what gets in the way or doesn't work? We also asked carers and providers to say what they would like to see more of, needs to change or should be improved. Without doubt the thing the received the most comments was transport

'Transport – this is important – when things go wrong it has a big impact'

'Getting to places is difficult as often I need support when I'm there and help to get on transport, I often have to get a taxi which is expensive, and the vehicles are often not the best'

'Ring and Ride don't turn up or if they do they don't like to wait, I also have been told we can't take you there because "it's over the boundary" '

'I don't trust taxis to go places when I am on my own'

'The availability of transport to and from the centre is limited as is transport to appropriate activities within the community this limits opportunities'

'We have our own transport but people also use taxis. These can be difficult to access and there have been so many times when service users have been left stranded'

‘Having (our) own transport is very expensive. Not only in terms of costs of vehicles, insurance and maintenance but also the resource needed to support with door-to-door pick-ups and drop offs’

This is an area that the EPT felt needed to be prioritised as part of the next steps for the review. Carers in the EPT felt that transport companies and services needed to understand the impact that late and unreliable transport was having.

‘When transport is late then this can upset medication routines which are important’

‘If people can’t rely on transport then they will be reluctant to take part in day opportunities, becoming more isolated and dependent on family carers – this will impact on the health and wellbeing of both the carers and the person being cared for’

There were some comments from older people who use services that they felt do not get the services and attention that other members of the community receive. Some felt discriminated against and had less opportunities than other people.

‘The council seem to have a distinct lack of interest in older people, we feel singled out and are treated differently’

‘I wish they would open up the rest of the rooms in the centre like they used to so we could do more (This is due to health and safety issues and not having staff to supervise)’

‘I think they ignore us because we are older people, it seems to me that older people are the ‘lost’ generation’

‘I’d like to do more things out of the centre, but I can’t because they haven’t got the staff to come with me. Age is discriminated against’

Carers and providers spoke about the perceptions about day services and their role in the support and care of people who them.

‘The perception of the community in that there seems to be a lack of understanding about why people attend day services, it is often seen as a ‘place to dump someone’ instead of a place where someone can go to enjoy themselves and meet people and make friends and be able to participate in activities and experiences and gaining a

degree of independence which they would not be able to do at home. This then leads to the staff perhaps being demoralised and lacking pride in what they do'

At the events there were ideas about what the activities and resources that are available to people. Some reflected on the changes that had been made during the pandemic and what they would like to do once again.

'We would like to put on more activities such as the music therapy, singing etc. but these were initially put on free of charge by an external person however we don't have the funding to allow this to continue'

'We used to use the little theatre but it's a bit difficult now because of the group sizes changing'

'I used to go to Remploy and would like to do more work'

One of the biggest barriers to people doing the things they want to do were facilities in the community. People valued and looked forward to trips into the community. They looked forward to trips to restaurants, museums and leisure facilities:

'I'd like to go to college and learn more about reading and writing and computers but there is no understanding of disability in the community college'

'When accessing the community there is a big difference with complex needs requiring 2:1 – (I) worry about reaction of public to challenging behaviour'

'Disabled toilets - clearly no consultation with disabled people. Ask people what they want and how it should be done'

It wasn't only the facilities that presented barriers it was also attitudes of the public and people working in mainstream and community facilities. They didn't feel welcomed and some were fearful and worried about people's behaviour and attitudes towards them.

'We often meet with negative attitudes in the community when we take people out. Some people don't know how to handle people in wheelchairs'

'Going out in groups can give service users more confidence but they can also meet with more difficulties in terms of attitudes from other people. Access for a single person in a wheelchair is easier than in a group'

‘It is sometimes difficult for people to do things if they have difficulty communicating
Public attitudes can be better and more accepting’

The EPT asked people about the use of and attitudes to IT. The use of technology was an important feature of the response during lockdown. Zoom and Microsoft Teams get people connected and activities like quizzes were popular. For younger people who use services there was a great deal of enthusiasm for using IT in different forms. IT and technology were seen as a core part of the services for some of the colleges and services for younger disabled people.

‘The availability of equipment is a problem could some of the older council equipment be donated to centres for them to use to teach people how to use (computers/ IT)’

‘Would be nice to give everyone i-pads but not enough funding’

‘The use of IT has presented some new opportunities. We did a zoom call on New Year’s Eve which we wouldn’t have done previously and that was very positive’

‘The ability to contact others via either a computer or mobile phone has been invaluable for us’

One severely disabled young man at a day centre used his adapted communication equipment to develop his own you tube channel:

‘I have my own you tube site and I want support to develop this promote this to other disabled people’

For older people and some carers it was something that less popular and some carers felt that IT should not be seen as an alternative to day services. The availability of equipment training and access to broadband were still seen as barriers.

‘Technology is helpful but it still needs a human element to get it to work’

‘IT challenging for older adults – resistance to change, scared of getting it wrong’

‘Our IT is out of date’

‘Only one service user has a phone but uses it to watch films on. He said he doesn’t have an email address but would like one to be able to email his Auntie who is in a home. I asked him if he uses WhatsApp or text but he said he doesn’t know how to

send a text. The service user has been going to the centre for 35 years, he spoke quietly but was very articulate’

‘We don’t have computers anymore and I liked using computers’

An important theme in the discussions with Carers was what they saw as the constant and relentless effort that was needed to get support. This was characterised as a “battle” or a “fight”. There was a sense that resources and reductions in money available for packages of care was the reason for this. Some felt that this brought uncertainty to their lives.

‘It’s a constant battle and fight for Carers’

‘Social work delays – life has to go on despite waiting for a package of care to be agreed

Social workers only get involved when things become urgent – enormous cost of this on carers’

‘Carers (need to) have support with making decisions in looked after people’s lives’

‘Unable to progress through adult social care. Huge delays to get an allocated social worker

A consistent point of contact with social services, it seems just as I’m getting somewhere the social worker changes’

‘The ability to get help and assistance when I need it not just the frustration of an answering machine which you end up giving up on after an hour, if you are not cut off, this just increases frustration and makes the situation worse for people’

They also voiced concern over the families that less able to advocate for the person they cared for and themselves.

‘It is often a case for carers that they have had past experience of ‘the system’ which can in itself be an obstacle and many people just don’t bother to ask for help and assistance as they get fed up with being told NO!’

The schools and colleges spoke about the transition from childrens to adults services. This was seen as a time of big change for young families and for young people. They wanted to see a smoother transition from education into social care.

‘We have to avoid the closure of the EHCP feeling like being pushed off a cliff’

‘She’ll just spend the rest of her life sitting on a sofa’

‘Stop young adults being stuck at home where their health and behaviour deteriorates and families struggle’

At one centre it was clear that staff felt there had been a reduction in the range of activities they could offer and the impact of what they are doing

‘Ideally there would be more opportunities for people to do things outside of day centres’

‘Used to go to the centre to learn new skills but that doesn’t seem to happen now’

‘Being able to have enough funding to be able to put on worthwhile activities’

‘What’s on offer doesn’t always match interest or what’s best for an individual’

‘People would like to come in on a Sunday’

‘We join up with another centre to do inter centre activities’

In part they saw the difficulties in recruitment and the levels of staffing available as restricting opportunities for those with complex needs, particularly in the community

‘1:1 support is sometimes needed when accessing the community this is often not possible due to the availability of staff’

‘Not so much going on because of staffing’

‘Do they have enough staff? It’s difficult to quantify’

‘The number of staff available makes it difficult to take people out this can be disappointing to people when the plans change’

Other groups spoke of the difficulties in finding things to do in the community that would be of interest to people and that could meet the needs the service users

‘Lack of information as to what is out there’

‘Perhaps there should be a dedicated person or small organisation which can work with service users to provide information of available services’

Some carers felt that perceptions about risk and health and safety were a barrier to people being able to do things in the community.

‘Issue with council run services is often the amount of ‘red tape’ involved in getting things done, e.g., expense of getting someone in to change a flashing light fitting, having to wait until there are several jobs to be done to keep the costs down’

‘Lots of risk assessments because of the complex needs’

At many of the events people spoke about the quality and commitment of staff at the centres. They valued those with experience of working with people with complex needs and recognised the range of skills and knowledge that was needed to deliver quality care and support.

‘Day opportunities provide more for individuals than just building based services, often the carers treat working at centres as more of a ‘vocation’ than a job’

‘Those with direct experience of the problems involved relate differently to individuals at the centre, staff awareness of issues’

Carers felt that skills, knowledge and attitudes of staff were crucial for quality services and that this was an area where improvement was needed in some areas

‘Unfortunately, not all council staff are inclusive’

‘Staff need to access more training’

‘Provide a safe environment for those that are more vulnerable than others, this reduces the carers anxiety and the anxiety of the service user’

For Carers they valued continuity of care and service provision. They felt this was essential for both the person attending the day service and for themselves. Change, cancellations and uncertainty disrupted lives and caused upset and anxiety in families.

‘Continuity – what’s there today might not be there tomorrow’

‘If you have a routine, you can occasionally break it but without routine things are uncertain

Having a routine for service users is often helpful for them but also having a break from that routine can help, gives people something to look forward to’

‘Continuation of provision, the uncertain future of both day care and funding can be very stressful at times for those who use the services’

‘We have a service user forum to share ideas of what to do. It helps to fill in the gaps in people’s lives. One of the biggest gaps we have seen is access to physiotherapy so we have arranged funding to run physiotherapy and speech and language sessions at out hub. This has taken a long time and a lot of money to do’

Across the engagement events carers and providers spoke of the crucial role that social workers play in assessment, reviews and signposting. Many felt that people had limited access to assessment and review and that this was causing problems for families and for services.

‘Assessments not being complete in a timely way’

‘More referrals to appropriate services are needed’

‘Young people are leaving education without a plan in place’

Carers and providers also felt that there should be more opportunities for people to have more choice and control over how packages could be improved. Some providers wanted a more personalised approach to care planning and assessment and across carers and providers there were suggestions for improvements to the way in which care is planned:

‘An Increase in joined up working with others, such as when individuals transition between children and adult services’

‘All should use individual development plans and be outcomes focussed’

‘Avoid using catch all terminology (treat people as individuals)’

‘Citizens don’t understand what a direct payment is’

‘Direct payments don’t cover access to costed activities. People have to pay for activities from their own benefits’

This programme of engagement has highlighted the wide range of services there are in Birmingham. However many felt that benefits and diversity of services were not well understood by families, people with social care needs, providers or other professionals working in Birmingham:

‘More awareness by the public of where services are and how they can help’

‘Having pride in the services provided this applies to both staff and attendees’

‘Communication with families is paramount’

Across the events there were ideas and suggestions for changes or improvements to services to meet the different needs in the community:

‘Having an age-appropriate setting allows people to be able to relate to the others around them’

‘Ideally the activities and setting should be flexible and adapt to the needs of individuals’

‘One size or type of care does not ‘fit all’

‘Dedicated transport for older adults’

‘Make day services more attractive to younger people’

‘Sitting services for when people can’t get to day centre for periods of time’

‘Some people have the effects of age before their time and so skills and activities have to adjusted to meet the individual’s needs’

They also wanted more opportunities to take part in activities away from day centres and be part of the wider community in Birmingham

‘The ability to take people out more to do activities that they enjoy and want to d’

‘“Forge better community links’

‘Accessible information for families, professionals’

‘Promote existing services’

‘Would like to have more facilities in the community for people such as changing places, an increase in accessible spaces and buildings, shops etc’

‘Help from organisations who have an understanding of a person’s disability or individual needs’

‘There needs to be more understanding of the problems (people and carers) encounter’

‘Places where adults with different diets can go e.g. blended foods’

At one of the events for providers they described “what good look like” for them

- A service where reliable transport to and from, and during the day at the centre is available
- A ‘joined up’ service where individuals are picked up from education and moved on to a day service with minimal break or disruption
- Encouragement is given to service users to allow them to be as independent as possible
- A person-centred service. which is age appropriate
- Where staffing levels are appropriate for the individuals it serves, and the equipment is kept up to date
- 100% person centred and fully resourced

They also shared the things they do to support people and families

- More family forums with info about benefits, advocacy, health and other issues
- Need a day opps brochure
- Open door policy for families (to discuss issues and feedback)
- Private social media accounts for families to network
- Feedback from families, satisfaction surveys, publish results in a newsletter, easyread, e-mail and post

The voice of future day opportunity users

An important part of the review was to speak to younger people who might need day opportunities in the future when they leave schools and colleges. Two members of the EPT team who had attended specialist education recently and they held events at 6 schools and colleges supported by commissioning officers.

We adapted the questions for this audience focussing less on the experience during the pandemic and more on what is important for them in their lives. The colleges provide for a wide range of special education needs as well as complex physical disabilities and conditions. We worked closely with the providers to enable the young people to give their views and we are grateful for their assistance in enabling these young people to have a voice in this review.

The EPT members asked what is important to you?

- Having an education
- Getting a job
- Being part of something
- Being seen
- Being respected
- Making sure they (young people) have a choice
- Having a relationship
- Volunteering
- Travelling
- Going on the X factor

What do you enjoy doing?

- Running
- Drama
- Going to the gym
- Listening to music
- Making music
- Being by myself
- Gaming
- Watching youtube

We asked people what aims and ambitions do you have for yourself? This varied enormously across the events. Here is a selection from two of the centres for people with autism and learning disabilities

- I want to be a mixologist
- I want to be a gardener
- I want to get money
- I want to get the bus by myself
- I want to know what I want to do because I don't

- Work with cars
- Go on holiday
- Have my own company

The people who attended the schools were encouraged to be ambitious and plan for the future. The staff felt this was an important role for the schools and colleges and they worked with pupils and families to see the strengths and skills that they do have and help them think ahead for life after graduation. The people the EPT met were also asked what help do you need and the staff at the colleges also gave their views

- I need my mum and dad to take me places
- I need help talking to people
- I need help with my anxiety
- I need help with cooking and tidying my room
- I need help getting changed
- Doing travel training
- I need help with the internet

The people the EPT met were also gets in the way of doing the things you want to do?

- Not knowing what is out there
- My mum not letting me
- Fear
- Money
- No car (or transport)
- I get scared in new places

From the discussions at the schools and colleges equipment and technology were important in enabling people to participate. The EPT asked what technology do you use and the staff at the college also spoke about this?

- ICT pads
- Big screens
- Switches (to let staff know if you are happy or sad, feel safe or unsafe etc)
- Interactive magic carpet – can also be controlled by eye movement
- The Day Care centres need to have the same equipment in order that the Young People can
- continue to grow and not lose the skills they have developed at college.
- You Tube

The schools and colleges had specialist equipment and facilities to help with communication, personal care, moving and handling and feeding. Sensory rooms and other equipment helped with stimulation and learning skills to socialise and engage with others. There was a sense from those in the schools and colleges that the provision for young people is different to the opportunities for adults who need support and that these facilities are less available.

‘The activities and support provided prior to graduation often does not match up with the support provided after’

‘Some services which are provided at education facilities are often not provided when attending a day service, such as the availability of health professionals etc’

The staff at the schools and colleges talked about the work they do to support carers and parents to prepare for the future. They wanted them to be aspirational for their young people and see the strengths and skills that they had. They often felt that this was difficult for some parents because they were fearful or anxious about the risks and the challenges that their children faced. The staff felt that the EHCP plan process and system was important in preparing families and they wanted to be more involved in these. They felt that often they were not effective in understanding the opportunities or in preparing families for the differences in the support that was available after graduation. This was a missed opportunity to support in this transition and to maximise independence of young people.

‘Invite Day Centres into the colleges, so they can see what happens there so they can create similar in the Day Care Centres’

‘Provide Student Passports (the HIVE College do this) with important information regarding the student, that can be shared with others’

‘There are limited facilities that meet the needs of our students. For example: they need medical help, such as tube feeding and the providers don’t want to take on the training as it is a big responsibility and then keep up with the standard of care’.

The next steps

This review and the extensive programme of engagement events, has brought together a wide range of people and organisations with a keen interest in day opportunities in Birmingham. Feedback on this approach from the people involved in the Empowering People Team, commissioners and providers has been positive saying they benefitted and valued working in this collaborative way to understand the impact of the pandemic and to

understand the benefits, opportunities and challenges in delivering day opportunities across Birmingham. They want to continue to work alongside the Council in this way.

In this spirit of co-production, the intention is that this report from the EPT and Red Quadrant will inform the next stage in Birmingham City Council's approach to day opportunities in the city. The views, ideas and shared experiences expressed by the people who use these services, the carers and staff have been wide ranging and detailed. EPT members have contributed their own views and they have reflected on the feedback they heard in the events identifying a number of important areas, themes and priorities for further action.

Main themes and the priorities for further action

The pandemic and the temporary closure of day opportunities had a major impact on people using centres and their carers. It was a very difficult time for staff and other professionals involved. Initially there was a lot of anxiety and confusion and there was a sense of crisis. People who relied on these were also worried about their physical health as many were identified as clinically vulnerable. Day opportunities were their normal enabling connection to others and without this, they felt isolated and fearful.

Providers and the council came together to find new ways of supporting people and their families. People across the engagement sessions spoke with pride at the way staff, the council, commissioners and families collaborated and supported each other. The zoom sessions, meals, activity packs and garden visits were greatly appreciated and meant that many received some support through very difficult times. Now people have returned to day opportunities, providers are reporting changes in the people they support, with people still worried about returning to services and noticing significant declines in social and day to day living skills. Mental and physical health had declined for many and they felt some lost confidence and the progress they had made through attending activities. The centres for older people spoke of increased needs of the people returning to them and a rise in the numbers and severity of dementia.

People using day opportunities spoke passionately about how much they valued the support they received. It is their community, it is where they meet friends to do the things they enjoy with other people. Carers saw day opportunities as essential services, enabling them to have a quality of life outside of caring. It allowed them to do the things they needed to do in maintaining their own health and wellbeing, as well as everyday tasks for themselves and their families. They said that when the person they cared for was attending day opportunities they were comforted that the person they cared for was in a place of safety, with friends and others who cared about them and were participating in a life away from the family which was important to their wellbeing and their growth as individuals.

Carers could connect with others in similar situations to themselves, sharing their experiences, supporting each other and finding out about other services and opportunities. Some spoke positively about the role of family support workers that some providers had employed. These played an important role in getting a broad range of support, advice and signposting to help them navigate the complex system of care. Knowing what services are available and what facilities there are in the community was something that many felt could be improved and was essential if people were able to have choice and take more control of their care and support.

Many carers felt that they had to fight to get the services that they felt were essential to enable them to undertake their caring roles. They valued continuity and certainty and felt that the process of assessment and review was difficult, time consuming and brought worry and anxiety that packages of care would be cut or changed. The benefits of direct payments and personal budgets was not well understood. Carers valued the services they had and were worried that those without help to navigate the system or without the determination and energy to persevere through the system were left behind. They were afraid that those voices are not heard. Providers were also concerned about the access to social work assessment, review and referrals. This led to delays and uncertainty for families as well as for services in planning and making continuity of care difficult to achieve.

Transport was the most talked about issue facing people and the area of greatest dissatisfaction. Getting to and from day opportunities was a daily challenge. Some day opportunities provide their own buses, but these are costly and the logistics to meet everyone's needs was challenging for providers. Taxis were unreliable and often were not suitable for the needs of person or the equipment was faulty. There were some positive experiences of using public transport but many, many more example of failure including buses not prioritising people in wheelchairs, equipment being faulty or not fit for purpose and generally a lack of understanding of how difficult and worrying people with a wide range of disabilities find it when using public transport.

Failures in transport meant that plans had to be changed and people left stranded, but it also meant things like medication, feeding and personal care were disrupted and this could present risks for people. The EPT felt strongly that they wanted this to be one of the priorities following this report and that the transport providers are engaged so that they could hear the issues and understand the impact.

People using day opportunities wanted to do more in the community. Transport was an issue but there were other barriers. Attitudes in the wider community to people with disabilities was a big theme. People using services and staff had experienced discrimination and aggression from people in the community. Physical accessibility and the lack of facilities prevented people from using some shops, restaurants and public buildings. Other issues were a lack of changing places around the city and the inability of venues to meet dietary needs.

A theme across the engagement events was a perceived lack of understanding regarding the importance and benefits of day opportunities. People wanted personalised support that meant high levels of training in a wide range of support and care skills. Communication and specialist skills in areas such as acquired brain injury, autism, cerebral palsy, learning disability and dementia were needed. Physiotherapy, speech and language, diet, feeding and personal care knowledge and skills were seen as being important. Having community bases like day centres provided an opportunity for “hubs” in which people could get a range of care, health and other support they wanted. Some services provided some of these and others said that they were working to try and access these.

The engagement events with young people and staff at schools and colleges highlighted the importance of focussing on outcomes and having the right skills and resources available to support people with complex care needs. Young people faced many of the same issues and challenges. They also spoke with passion and enthusiasm about the friendships and sense of community that they experienced in education settings. They were encouraged to be ambitious for themselves with many saying they wanted to be more independent getting further training and education, finding employment and participating in activities in the community.

The education staff felt that supporting parents and carers to see the strengths and abilities of young people was a key part of their role. They recognised that this was difficult for many parents who wanted to protect the people they looked after, wanting to minimise the risks they face. The staff wanted to be more involved in education, health and care planning and were keen to share the knowledge and experience they had with adult day opportunities. They were also aware that there were not enough opportunities for those with the highest levels of needs and appreciated that for parents the transition to adult services was like ‘reaching a cliff edge’.

Day opportunities are seen as a necessity to enable people with care needs and their carers to have fulfilling lives, and importantly maintain their health and wellbeing. As such the services and staff need to have the status, training, equipment and resources to fulfil these complex roles effectively. The participants wanted the ‘system of care and health’ in Birmingham to recognise and value the role they play and afford them the status alongside other regulated care and health provision.