

My Day My Way



A look at daytime activities for people with a learning disability across Cwm Taf Morgannwg

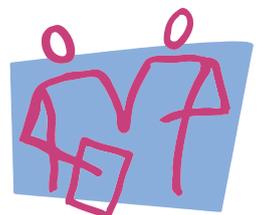
Phase 1

November 2020 – March 2021



Cwm Taf People First

People First Bridgend
Pobl Yn Gyntaf Pen-Y-Bont



putting people first
rhoi pobl yn gyntaf

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Summary of Key Observations

Throughout the conversations and data collected across the My Day My Way projects phase 1 activities the following key observations were identified. These are explored in more detail within this report:

Pre Covid-19:

- The largest indicated daytime activity pre Covid-19 was attendance at a Local Authority managed Day Centre provision
- Volunteering and Work are valued as a good daytime activity for people with a learning disability, but often what is meant by volunteering and work is unclear and subjective. Many expressed a keen interest to re-engage or newly engage in a form of volunteer or work placement post Covid-19
- 22% stated that they attend(ed) college pre Covid-19. There appears to be inconsistencies in relation to further educational experiences within a college environment. Whilst some reported high levels of satisfaction with their college experience, expressing a deep longing to return, others highlighted disappointment after not being able to undertake the course of their choice, or having to finish college because they had completed all that was on offer to them without a clear understanding of what they would do next
- Seeing friends (77%) was the largest reason people with a learning disability enjoyed engaging in their daytime opportunity pre Covid-19. This was followed by being active (72%)
- Having the right support is vital for empowering people with a learning disability to engage in meaningful and purposeful daytime opportunities. Family Members (59%) were highlighted as the main source of support for people, followed by dedicated Support Workers (57%) such as Personal Assistants and Day Centre staff

During Covid-19:

- Many people engaged with the project have found lockdown boring and have not been able to engage in their usual daytime activity at their pre Covid-19 level, if at all
- Some individuals reported that they have gained weight over the lockdown period and that they have less motivation to look good
- Many indicated that they had been confused during the Covid-19 pandemic due to a lack of clear information that they could understand fully, and a lack of communication from daytime opportunities service providers
- Digital Connectivity has been a lifeline for people with a learning disability for connection with others, and as an avenue for them to have their voices heard
- Not all people with a learning disability want to be engaged digitally, and therefore a diverse range of engagement tools are needed to allow people to choose how they want to participate and be involved. This choice then provides people with a sense of ownership and value

After Covid-19

- 87% of people with a learning disability engaged in the project indicated that they would like to change something about their day as things move out of lockdown and back to some form of normality
- 77% stated that they would prefer to meet face-to-face rather than digitally as restrictions start to ease and lockdown ends. However, there was an appreciation for being able to meet digitally through the lockdown periods, with many expressing that this has allowed them to meet new people from other areas
- When considering what would make a good day for people with a learning disability after Covid-19, responses were largely diverse reinforcing the need for person-centred approaches. However, spending time with friends and family (61%) and eating out/socialising (67%) featured as clear priorities for people with a learning disability highlighting the importance of social connection and interaction
- The importance of travel was highlighted as the key to allowing people with a learning disability to do the things they would like to do post Covid-19, including participating in community activities, visiting new places and going on holiday
- A number of people with a learning disability are keen to return to their pre Covid-19 day centre provision so that they can see their friends, the staff, and have some form of regular routine back in their lives. However, for others, this break from day centre has allowed them to consider undertaking alternative daytime activities such as volunteering or paid work post Covid-19



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Project Background

Social Care for adults with learning disabilities has typically consisted of engagement in some form of day centre service or structured daytime opportunity that aims to increase the potential for social interaction and the development of new skills, providing more purposeful and meaningful lives for those who access them.

There is no, nationwide, systematic way of delivering such services, or definition of what they should look like, instead their structure is largely determined by service providers of which the majority are run or commissioned by local authorities. This freedom of delivery provides unique opportunities for such provisions to be varied and diverse in the hope that they are needs driven, offering elements of choice that allow the individuals who access them to reach their personal goals as well as complimenting interests and desires. However, the localisation of design and delivery has also allowed a number of day centre services and daytime opportunities to become out-dated and ineffective.

Demand, and to a certain degree, social expectations, have started to transition into more person-centred models of working, capitalising on the idea of providing Voice, Choice and Control to users of services so that they can experience some level of ownership over their lives and making their daytime activities more meaningful and purposeful. Although being backed by the Social Services and Wellbeing Act (Wales), 2014, there still appears to be a delay in these person-centred models of service delivery becoming a reality. As with many service-based provisions, one of the biggest elements that has hindered the successful transition into a more person-centred approach has been a distinct lack of resources: finance, staff, buildings, transportation etc. Increasing pressure on local authorities to reduce budgets and save money has led, in some cases, to favouring larger generic provisions which can serve increased

numbers of users rather than smaller, person-centred, needs-based, targeted provision, allowing day centre services to become a destination or holding place rather than a mechanism for personal growth and development. Additionally, the desire to cut back and reduce costs has also led to reduced hours of care and less stability in the care package on offer which has left parents and unpaid carers filling in the gap to try and give their loved ones a sense of a meaningful life. Key findings from the Welsh Government's, Learning Disability Improving Lives Programme Review, June 2018 further suggests that this transition to the person-centred approach is yet to be achieved.

It states:

The overriding response from parents and carers regarding their lived experience was that it was a “fight” and a “battle” to get the right services and the right support [and that] services were generally not seen by parents and carers as person centred and flexible to adapt to people’s needs

These issues with day centre services/daytime opportunities have recently been exasperated by the Covid-19 pandemic. During this time of unprecedented challenges and uncertainty, the charity Mencap conducted a survey to capture and understand the experiences of those caring for someone with a learning disability through lockdown. In a review of the survey's findings, ITV News (August 2020) reported that 'Social care cuts [have] left people with a learning disability 'forgotten' in lockdown.' Within this report, Edel Harris, Chief Executive of Mencap suggested that:

'social care has had decades of underinvestment - [as a result of the Covid-19 pandemic there] are clear signs that the system has broken and people with a learning disability and their families are paying the price - social care needs significant investment now and a bold plan for reform for the future. People with a learning disability and their families must not be left behind in lockdown'.

more than
65%
of people with a learning disability have had their social care slashed

The report further highlights that 'more than 65% of people with a learning disability have had their social care slashed by at least half [during the pandemic, and that] the amount of social care support their loved one received [or continues to receive] from their local authority has decreased a lot - [as a result] cuts to day services, personal care in the home and respite for carers have had a devastating impact on people with a learning disability and their families'.

Whilst the pandemic has set in place a number of unanticipated challenges for the health and social care sector, including provisions and services run and commissioned by local authorities, it has also provided some breathing space in which to reflect upon and re-evaluate the effectiveness of the day services on offer to people with a learning disability. Due to the strict government guidelines that were issued in response to the Covid-19 pandemic, many day services and daytime opportunity provisions across the Cwm Taf Morgannwg region were closed to adults with learning disabilities except for in exceptional circumstances for those with the most complex needs.

This closure/reduction of services, whilst necessary, has caused many disruptions to the lives of people with learning disabilities, leaving some struggling to cope with the changes to long engrained routines; grieving a loss of independence and identity; and forcing the transition into full-time unpaid caring roles for some parents and carers. This has left many craving a return to a day service of any kind as a means of missed connection, social interaction, and respite.

As a response, the My Day My Way project was developed as a mechanism to capture the first hand experiences of people with a learning disability in relation to the day services and daytime activities they engaged with prior to lockdown; how their lives have changed as a result of the pandemic related government restrictions and ongoing guidelines; and what, if any, changes they would like to see moving forward as the health and social care sector develops a 'new normal' service delivery model for a post covid-19 world. Spearheaded by Cwm Taf People First and People First Bridgend, the project has interacted with over 60 people with a learning disability across the Cwm Taf Morgannwg region, to undertake the projects phase 1 activities.

Enclosed within this report are the stories, thoughts, ideas and opinions of people with a learning disability brought together under a series of common themes to help service providers understand what really matters to the users of their services, and the things that people with a learning disability truly value in terms of creating a meaningful and purposeful life.



Project Vision and Outcomes

Vision Statement

It's MY day - let's do it MY way

To challenge services to provide more diverse, person centred and meaningful daytime opportunities by empowering people with a learning disability to be fully involved in decisions about what they do during the day, included in the wider and ongoing evaluation of current opportunities available and have their voice heard and experiences considered in the planning and design of new opportunities within the Cwm Taf Morgannwg Region.

Project Outcomes

To ensure that the My Day My Way project is effective in meeting its vision, the following outcome statements have been identified as impact measures for the project's activities:

- to explore what people with a learning disability did prior to Covid-19, do now as a result of lockdown restrictions and what a good day would be like for them in the future. Through this process the project will take into account what is 'realistic' and look at how to manage expectations.
- to develop a mechanism to have open, honest and effective conversations with people with a learning disability, parents/carers and service providers to find out the impact of Covid-19 and how we can work towards a suitable and effective recovery plan together. Project phase 1 will identify and trial a range of engagement and evaluation techniques to be able to outline the best methods for capturing citizen voice (information and experiences) and feeding that into relevant audiences for future development and action.
- to overcome the evolving technology and communication issues that have previously been identified, the project will purchase a remote access package which will allow safe and appropriate access to the IT equipment of others and ease the virtual joining process. This will allow more people to be involved in the project.
- to build the IT skills of people with a learning disability around the necessary technology and communication platforms to allow them to be seen and heard as experts within service design and delivery models, ensuring that they have Voice, Choice and Control over their lives.
- to analyse the impact, value, challenges and barriers of employing people with a learning disability to co-facilitate on such projects in a meaningful, non-tokenistic manner, that helps them to build skills for future employment and volunteer placements, as well as other areas of their lives.
- to collate and analyse all information and data collected through the project to identify key themes and recommendations to develop daytime opportunity services to support an effective Covid-19 recovery. A dedicated My Day My Way report will be written and circulated following completion of each project phase to be circulated to the relevant stakeholders, service providers and decision-making bodies.
- to identify future and ongoing opportunities to co-produce and co-design new approaches to shape the future of daytime opportunities in a way that meets the individual needs of people with a learning disability across the Cwm Taf Morgannwg Region.

Project Phase 1 Methodology:

A Co-Productive Approach

Co-Production is a working model that allows for the re-balancing of power structures, creating a level playing field that opens opportunity for diverse, and uniquely qualified minds to come together, discuss and identify shared solutions to overcome any issues, problems or barriers that may exist and drive improvement across all areas of the Health and Social Care sector. In practice, co-production involves people with lived experiences (users of services) being informed, consulted and involved from the start of any piece of work that may affect them or their peers, and then working alongside, as equals, other key stakeholders including service providers, senior decision makers and professionals throughout the whole project cycle, to its completion.

To work in a co-productive way, the Co-Production Network for Wales offer 5 key guiding values to consider:



Value everyone and build on their strengths



Develop networks of mutual support that expand across silos



Focus on people's lives, not systems



Work on the basis of great relationships built on trust, that share power and responsibility



Enable people to be change makers

Taking these points on board the My Day My Way project wanted to ensure that the development of its co-productive approach was fully directed by the notion of focusing on people's lives, not systems to draw insight into the experiences of those who use day services/ daytime opportunities across Cwm Taf Morgannwg. To do this the project was built on the foundational principle of empowering people with a learning disability to be recognised as experts and truly understanding the value of their life experiences and wider contributions. In turn the project aims that its co-productive approach will also provide space to empower people with a learning disability to be the driving

force of future service change to help them live more meaningful and purposeful lives.

Within its phase 1 activities, the My Day My Way project has initiated a number of key ideas that has helped the early development of its co-productive approach. This has included employing people with a learning disability as Project Explorers; creating new and strengthening existing partnerships; and exploring a range of engagement tools to ensure inclusivity, accessibility and the opportunity for people with lived experiences to be heard in a way that suits them. Each of these co-productive ideas will be explored in the following sub-sections.

Led by Experts:

Employing People with a Learning Disability as Project Explorers

As parts of its co-productive approach, the My Day My Way project recognised that people with a learning disability were experts by experience, and therefore the fundamental ingredient of achieving the projects vision. Whilst that may seem obvious, there is a great deal of complexity and consideration to be acknowledged in ensuring that the project processes allow for full and meaningful involvement in a way that suits people with a learning disability, without tokenism and prior agenda bias. As a means for overcoming some of these complexities, the My Day My Way project actively recruited 3 people with a learning disability to drive project activities across the region in co-facilitation roles titled Project Explorers. The role of the Project Explorers was to lead project design and delivery through phase 1 (and beyond) activities, having ownership over all elements of the project including project name and logo design, engagement tool creation, delivery and facilitation with their peers and becoming a representative voice for them in both internal and external decision making processes in relation to daytime opportunities.

Within this initial phase of the project, there was an understanding that Project Explorers would need elements of support to empower them effectively to undertake and fulfil the duties and responsibilities of the role. Below are a number of mechanisms put in place to ensure the success of the Project Explorer roles, alongside some of the challenges that were encountered:

CHALLENGE: Managing Money

Through the recruitment phase of the project it became apparent that many people with a learning disability didn't possess the skills and understanding to manage money well – some openly expressed that they had no interest in money and didn't really know what it was. Therefore, it was important that the project ensured that relevant safeguards were in place for Project Explorers to be paid. This included liaising with family members, advocates and support staff who were responsible for the individual's money, and in some cases paying Project Explorers as sessional workers rather than employees. Following learning from the journey of the Project Explorers through phase 1, Money Management has been highlighted as a personal/professional area for development and further training in Phase 2.

CHALLENGE: Remote Working

Covid-19 has proven to be a challenge for all of us over the last 12 months, with a shift to remote and virtual working. Project Explorers were faced with starting employment on the project without being able to physically meet with their People First support workers and having to develop needs-based ways of working so that they could effectively undertake and fulfil their duties. The project recognises that this would have been made even more difficult without the direct support of parents and house staff in helping Project Explorers attend virtual meetings and have their voices heard.

CHALLENGE: IT Skills and Internet Connectivity

As a result of the need for remote working, it was highly important that Project Explorers were able to connect with the wider project activities through various virtual platforms. To aid this, where appropriate, Project Explorers were equipped with digital equipment and offered remote training to be able to use it effectively. In some cases, this has continued to be an area of weakness and the project is aiming to look at developing more robust training options in Phase 2.

CHALLENGE: The Benefits Trap

In line with the Therapeutic Earnings Allowance, Project Explorers were employed on either a sessional worker basis or under contract of 2 hours per week at £10 per hour. The biggest challenge came from family members who didn't know about or fully understand the Therapeutic Earnings Allowance and therefore were against their loved one taking on the role in fear of it having an adverse effect on their benefits.

SUPPORT MECHANISM: Project Staff Support

To enable Project Explorers to lead the project effectively, individual People First staff were assigned as support workers to provide relevant support in both 1-2-1 and group contexts. It was also the role of the support worker to help the Project Explorer identify professional goals to work towards and provide support to help them overcome areas of weakness and develop wider employability skills for the future.

SUPPORT MECHANISM: Peer Support

As well as having People First staff support, it was also seen as important for the Project Explorers to have an opportunity to learn from each other and share ideas. The benefit of this has been invaluable and as the project moves into Phase 2, this is something we would like to develop further by providing Project Explorers a peer mentor to help them understand their duties and responsibilities as an employee and how they can further their career in the future.

SUPPORT MECHANISM: Personal/ Professional Development

In an effort to ensure their role was non-tokenistic, the project decided to do some work and research into the personal and professional development areas of the Project Explorers at the beginning of the project and then at incremental points to monitor progress. This is something that will continue to be undertaken through the proceeding phases of the project to help inform the development of project activities.

“I enjoy doing my job with People First and I have been good at meeting new people”
**Bradley, Project Explorer
Merthyr Tydfil**

Better Together:

The Importance of Partnership Working

To develop its co-productive approach effectively, the My Day My Way project acknowledged the value of involving and working with other key stakeholders. At the start of the project, the full project team undertook a review of the skills, knowledge and the potential reach they had as a way of identifying some key components of the projects phase 1 design. This review also revealed the project teams' limitations through skills and knowledge gaps and potential areas of under representation through its personal networks. Understanding the potential struggles that may be encountered allowed for the active engagement of a small number of project partners as a means to plug gaps and strengthen the overall outcomes of the work. In a broad sense, working with others allows for a diverse range of perspectives, ideas, experiences and opinions to be included and considered within the wider project conversation so that the overall project vision can be achieved holistically. This is something the project was keen to explore and develop, especially in terms of some of the anticipated recommendations and actions that may have been identified for work in later phases of the project.

For the purposes of the projects phase 1 activities, sharing the workload and involving others helped increase the reach and impact of participation. Project partners through their networks, had access to more/different people with a learning disability and were able to offer appropriate support to help them engage. This was crucial for the project in trying to reach a representative demographic across the region.



Better Together:

Developing Meaningful Project Partnerships

Great partnerships are built on a foundation of good communication and trust. In order to work together, everyone involved must fully understand the desired outcome they are working towards, and what they are required/expected to contribute. This could be as basic as contributing ideas and experiences, to delivering a detailed task or piece of work that feeds into the overall project vision. As part of this a number of crucial questions may be asked regarding allocation of resources (if available), individual capacity and time. For this process to work, honesty and transparency is vital.

As part of the project's phase 1 activities, a group of people with learning disabilities from across the region were brought together to form a focus group to develop a strategy for open and inclusive communication. Following a series of workshops this group developed some key principles for communication with and about people with a learning disability:

1. Know Your Audience:

before engaging with or speaking about people with a learning disability, know and understand the barriers and accessibility issues that may stop them being fully involved. This may include practical barriers such as how they will get to/join the meeting, but also social barriers such as intimidation, lack of confidence and the method of information dissemination.

Additionally, try to identify your audiences' true abilities. It can be easy to over/underestimate people's true abilities based on how they communicate. People with a learning disability can often present as fairly competent because they have learnt social scripts as response mechanisms to everyday questions and situations, however, can lack the deeper levels of understanding needed to effectively participate fully. Equally, the reverse can happen especially in cases whereby someone has difficulties in communicating their opinions yet has a deep awareness and understanding of what is going on around them. Therefore, when speaking and including people with a learning disability in your work, adapt your material to how people understand, not necessarily how they communicate.

2. Speak To Us:

if you speak to people with a learning disability in a way they can fully understand and be meaningfully involved, they will be able to respond for themselves. Many people with a learning disability reported that professionals often speak to their parents/carers or support workers instead of them and this made them feel undervalued and not respected. People with a learning disability expressed that keeping eye contact, being patient and checking understanding of what they had said, are all important points to consider when speaking to them. That said, when you are trying to obtain a holistic perspective of an idea, issue or potential solution, consulting and involving parents/carers and support workers is key, however, this should not be done instead of speaking to a person with a learning disability, but rather as an addition to.

3. Don't Use Hard Words:

people with a learning disability can sometimes find the words used in meetings and information shared difficult to understand. This is a particular issue when jargon, acronyms, and highly scientific/academic language is used. To help people with a learning disability be fully involved, break down hard words and create Easy Read versions of handouts, slides and information points for them to follow.

4. A Picture Speaks a Thousand Words:

to further help people with a learning disability understand the content of meetings and shared information, where possible, they request that relevant and appropriate images are used. This also allows for people with a learning disability who are unable to read join in and follow what is happening.

5. Treat Us As Equals:

people with a learning disability have a range of unique skills and experiences that can add value to any meeting, task, project or activity. As experts by experience they often have innovative ideas of how to overcome issues, as well as a personalised understanding of needs and wants. Therefore, people with a learning disability ask that no decision is made about them without including them. As equals, people with a learning disability also want to be given shared ownership and responsibility to meet the required actions, outcomes and vision of any piece of work.

“We are all different, and that’s a good thing!”



One Size DOESN'T Fit All:

Engagement Tools for Data Collection

When working in a true co-productive manner, there needs to be an appreciation and understanding that not everyone will want to/ can engage in the same way, and that this is ok. In fact, having a range of different engagement methods and opportunities to engage is a really positive thing for any project, especially when the desired outcome is to gather individuals' experiences and use them as a basis for both challenging services and driving forward change. This diversity allows you to collate and analyse a spectrum of data, from detailed statistical information that can quickly highlight basic trends, to more open and non-agenda driven dialogue that can provide context to the data and give an element of human impact.

As the My Day My Way project considered its co-productive approach against the desired project outcomes and vision, it was identified that a one size fits all methodology towards its engagement activities would not work; alienate a vast number of desired participants and result in a diluted set of findings. To help the project develop a range of engagement activities, the Project Explorers were enlisted to think about how best they would like to take part, and then to think about the best ways they could get some of their friends/peers involved. These discussions led to the project undertaking a three-pronged approach to its phase 1 engagement activities, with further scope and ideas to diversify this within phase 2 and beyond.

1. An Easy Read questionnaire:

The project team agreed that for some people a questionnaire would be a good way to collect a lot of data quickly, and to reach those who had dis-engaged with People First activities through covid-19 and the lockdown period. The Project Explorers took the lead on developing the questions and designing how the questionnaire looked, taking into consideration different people's abilities and what they felt would help more people complete it and take part in the project. Alongside the questionnaire a letter was also developed to give people a good understanding of what the project was about and other ways they could get involved if they wanted to. It was also agreed that the questionnaire would be sent out in 2 formats: in hard copy via post with a return envelope enclosed, and electronically via email. Questionnaires were anonymous in the hope that people would be more open and honest in their responses.

2. Project Explorer (Peer) Led Interviews:

The project team also agreed that the questionnaire wouldn't be suitable for everybody, especially those who struggle to read and write, and therefore wanted to open a platform for peer-led interviews to take place. This engagement option was also offered to those who completed a questionnaire but perhaps wanted to engage further and expand on their answers. Each Project Explorer was supported by a Project Support Worker who also took on the role of scribe within each of the interviews.

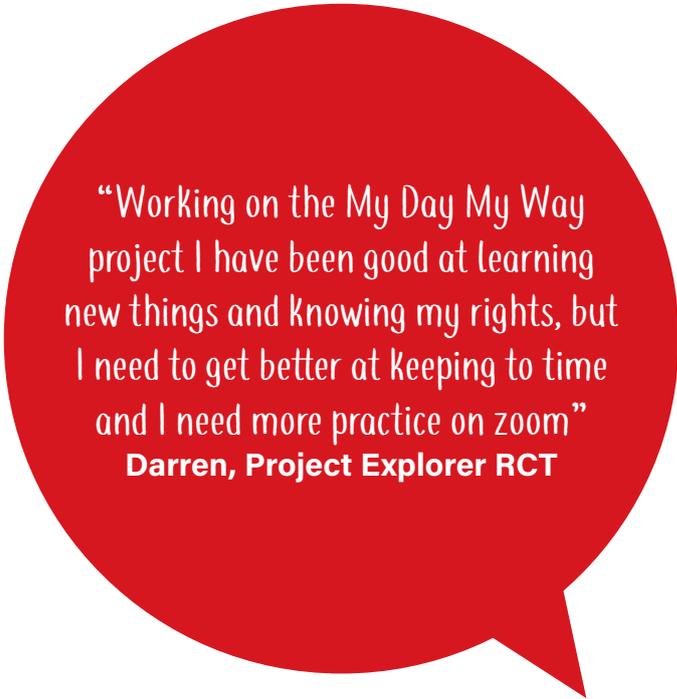
3. Storytelling:

Finally, the project team agreed that interviews may be too formal for some people to engage with the project fully, and so they wanted to explore the idea of storytelling as a data collection tool. Due to the tight time parameters associated with the projects phase 1 activities it was felt that this engagement tool should be piloted by a small group of people to ascertain its value for later phases of the project.

Therefore, this engagement tool was trialled by a small group of participants from the Bridgend area of the Cwm Taf Morgannwg region. A

member of Project Support Staff facilitated these group sessions that allowed participants to explore their own personal stories through sharing their experiences with others of life before Covid-19, during lockdown and what their hopes are for when some form of normal returns. An illustrator then pulled key pieces of information from the group storytelling sessions to develop personalised illustrated stories for the individual participants. Some of these illustrations have been used later within this report to help contextualise some of the data showcased.

Consent was obtained from all participants who engaged in any of the outlined engagement tools, and they were invited to be part of the approval team for this findings report.

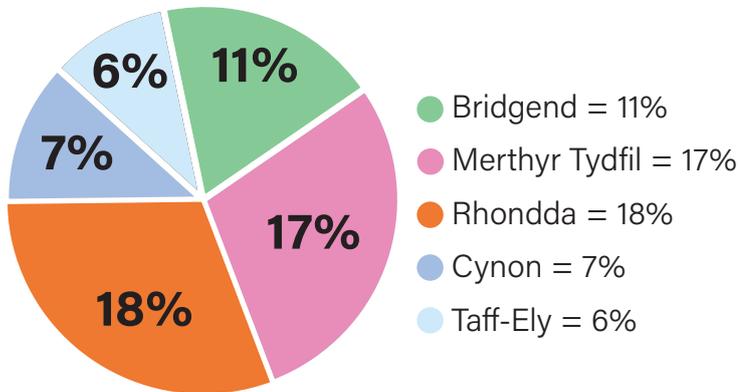


“Working on the My Day My Way project I have been good at learning new things and knowing my rights, but I need to get better at keeping to time and I need more practice on zoom”
Darren, Project Explorer RCT

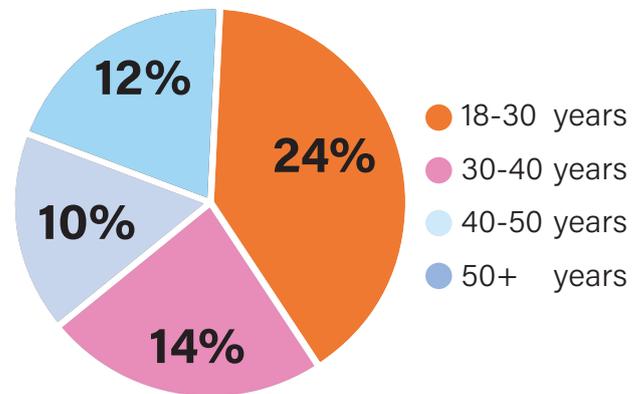
Project Phase 1 Findings:

My Life, My Story, My Future

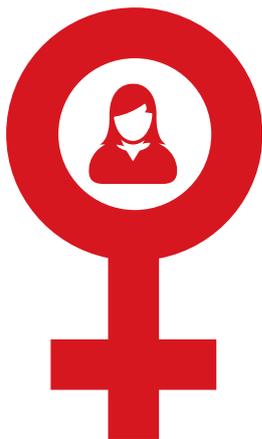
Regional Split



Age Split



Gender



Female 26



Male 34

Engagement tools used:



The three engagement tools used within the project provided a diverse range of rich data, both quantitative and qualitative, from which the My Day My Way project team have been able to draw its findings. As analysis began it was clear that information could be separated into three focus areas: life before covid-19, life during lockdown, and people's hopes for the future post covid-19. The following sections of the report outline the major findings that were identified, highlighting individual trends and themes upon which the reports conclusions and recommendations are built.

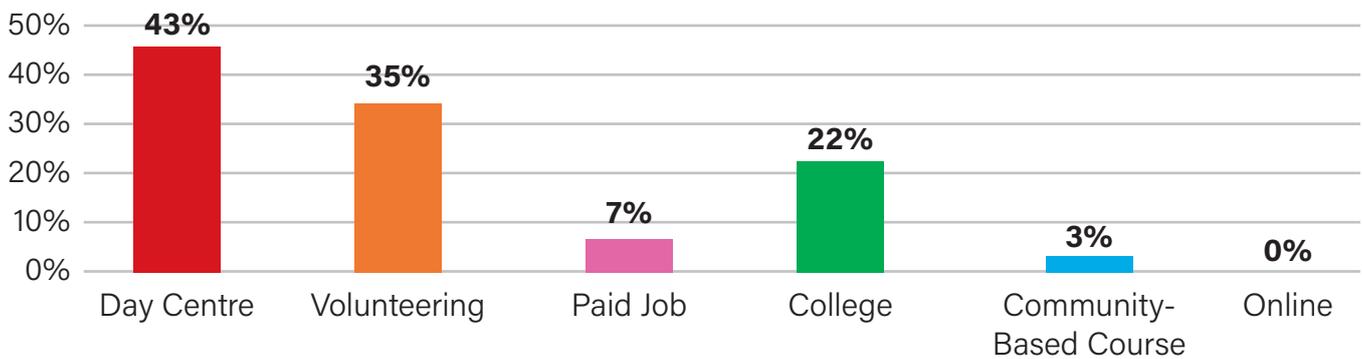
The Way it Was:

Daily routines of people with a learning disability before the Covid-19 pandemic

For many, life before lockdown seems like a distant memory and as such it has become a distinct life marker and/or divider in which people think about and categorise their lives: before, during, and after the Covid-19 pandemic. Whilst we might not be out of the pandemic fully, the language used to describe situations, thoughts, feelings etc. can usually be separated into one of these three time periods, and this was no different for the people with a learning disability who engaged with the My Day My Way project.

When thinking about life before lockdown the project asked individuals to consider three things: what they used to do during their day; what did they like about what they used to do during the day; and who supported them to effectively engage in their daytime activities. Each of these questions were explored within all three of the engagement tools utilised, with question responses from each tool being mapped into a central survey to collate the statistical data represented in this section's graphs.

Fig. 1 What People with a Learning Disability said they did during their day pre Covid-19



“I was going to Treforest Day centre five days a week where I was in catering. I cleaned and did the water in the saucepans, sweeping up and health and safety. On a Friday we had karaoke. After the flooding I went to Llwynypia, but I like Treforest best because I get to chat with friends and the day centre staff encourage me to do things”

Carl, RCT

“My college course ended in March 2020 because of Coronavirus and now I won’t return to college and I don’t know what I will do in my days”

Anonymous, RCT

In terms of what types of daytime activities people with a learning disability used to undertake, pre Covid-19, 43% of participants indicated that at least part of their week (1 or more days) consisted of attendance at a Local Authority managed day centre service. This was the largest indicated daytime activity.

Following this, 35% stated that they participated in some form of volunteer placement/activity. From wider discussion with survey respondents, it became apparent that some people who attended day centre identified what they did within day centre as either work or volunteering, especially when their day centre activities involved doing something physical such as catering, gardening or woodcraft, and where they received an attendance payment. Some examples of volunteering placements offered included the Wood-B project in Bridgend, the Greenhouses in Merthyr Tydfil and the Arts Factory and Lakeside in Rhondda Cynon Taf. Volunteering, and for some paid employment, were a hot topic with many expressing a wish to return to some form of work (voluntary or paid) and others who had never done either showing an interest in wanting to do something like this in the future.

Discussion about education as a daytime opportunity was met with mixed feelings by those who had participated in the project. Whilst 25% indicated that they engaged in some form of education as a daytime activity (22% college, 3% community-based courses), there was also a number of people with a learning disability who voiced disappointment in either being removed from education for various reasons, or not being given access to the course of their choice. Within some of the peer-led interviews, people with a learning disability discussed some clear aspirations for the future and many expressed a desire to learn new skills in an educational context. This was correlated by 38% stating that learning new things was something they liked about what they did during the day.

“My life was so busy before lockdown. I used to go to day centre and did a work placement with People First on a Friday. My favourite activity was going out for a meal and I love clothes shopping”

Julie, Bridgend

“I used to volunteer at the Lakeside two days a week and I really enjoyed the social side of going there, chatting to people, serving people, cleaning tables – I got to meet new people all the time”

Terri-Anne, RCT

“I get most enjoyment doing activities when my Personal Assistant (PA) is with me – but I like having the chance to try lots of activities”

Anonymous, Merthyr Tydfil

Additionally, seeing friends and being active ranked as the highest reasons people with a learning disability enjoyed the daytime activities they participated in. After enduring an extended lockdown period, it was evident that social connection was something vitally important to people with a learning disability, and that being able to spend time with friends engaging in fun activities of their choice was a clear theme that resonated across the different engagement tool methods, and across the three different time periods of before, during and after the Covid-19 pandemic.

Wider support was also recognised as a role of friendships however, the majority of people reported receiving regular support to undertake their daytime activities from Family Members (59%) and dedicated Support Workers such as Personal Assistants and Day Centre Staff (57%). Many recalled how they had missed contact with some family members and support workers through the covid-19 pandemic and lockdown restrictions, stating they were keen to return to some form of normality so that they could see these people again. This re-confirmed the importance of consistent support and relationship building in terms of empowering people with a learning disability to be able to engage in meaningful and purposeful daytime activities that keep them active and connected.

Fig. 2 What People with a Learning Disability said they like about what they do during the day

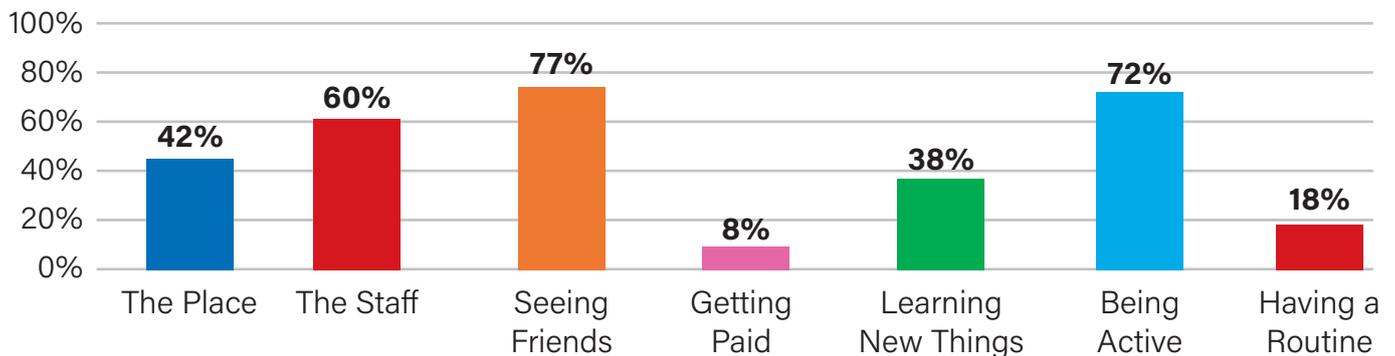
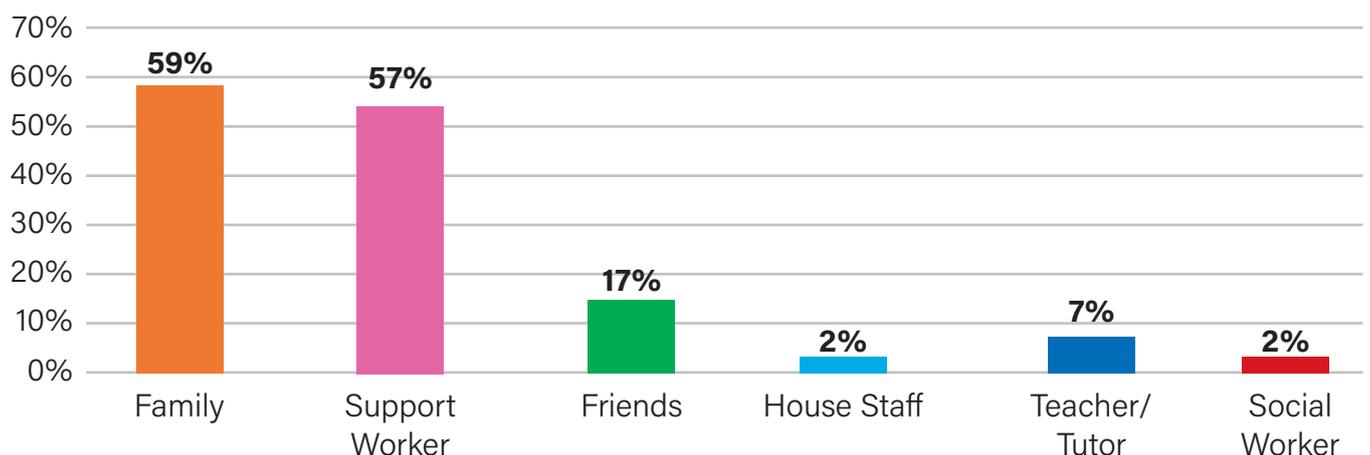


Fig. 3 Who People with a Learning Disability identified as their main sources of support to engage in daytime activities



The Things I Did Before Covid-19 and Lockdown



“I used to go to day centre five days a week. The day centre is good. I like the activities and I get to see my friends. Because of lockdown I had to stop going to day centre, and I really want to go back to day centre”

Luke, RCT

Life on Hold:

Daytime activities for people with a learning disability during the Covid-19 pandemic

As life in lockdown was explored across the three engagement tool methods, it was clear that people with a learning disability, like the majority of the wider population were bored, fed-up and in some senses grieving a loss of personal identity, independence and social connection. In addition, many indicated a level of confusion in regard to the pandemic, citing a lack of clear information and communication being received. Life was literally put on hold, and as such almost all daytime activities for people with a learning disability were paused. As the pandemic progressed and lockdown lengthened, provision across the region for those with the most complex needs and/or deemed most vulnerable were made available with strict measures for the prevention of infection spread put in place. For those who were able to access these provisions, they were often unable to do so at the same level they did pre Covid-19 and they were met with the reality of Personal Protective Equipment. However, for others, accessing the limited provision on offer was not an option and therefore they were left with little to do during the daytime.

Shielding was a topic that was discussed frequently, highlighting specific issues for those in supported living accommodation who were not able to form extended support bubbles with family members, even in periods of the easing of some lockdown restrictions. For those who were able to get out and about for their daily exercise, many expressed how this helped them to have something to look forward to during their day, but that as time had gone on, this had also become 'boring' as they had to do the same walk daily.

Within the storytelling and peer led interview engagement tools, people reported that they

were experiencing a lack of motivation towards self-care, with more than one female participant stating that they struggled to have the motivation to make themselves look good or to be glamorous like they used to before lockdown. Equally, many reported that they had put on weight during lockdown, citing the fact that they were eating out of boredom and that they were less active than they used to be.

“being in lockdown is boring. Life is so boring at the moment. I like to go out and meet people”

Anonymous, Merthyr Tydfil

As friendships and socialising with friends had been highlighted as a key component of a good day pre Covid-19, many people referenced missing being able to go out for meals or to coffee shops and pubs as part of their weekly activities.

“During lockdown I moved to a new house in a new area and couldn't say goodbye to my old friends. I hope when lockdown ends that I get to see them and that I get to make new friends”

Tina, Bridgend

It was clear that food and drink played an important role in allowing people to live a meaningful life as it was often a mechanism for them to see new places and to meet up with friends or spend time with family and support workers. On the other hand, many also reference how they had learnt to cook and bake in the house during lockdown and that this was an activity that had helped them stay busy.

What Life is like for me during Covid-19 and lockdown



"I enjoy new activities but at the moment I am unable to do most outdoor activities and cannot use day centre because of the coronavirus"

Anonymous, Merthyr Tydfil

You're On Mute! – the shift to a virtual world

As well as placing life on hold in many senses, lockdown opened the way for a more virtual way of working. Whilst seen as a positive attribute in the way it allowed for remote working and the continuation of jobs and industry, for some it became an isolating trap in which they lost all connection to the outside world. Digital poverty quickly became a buzz word across the globe and some of those most vulnerable to experiencing it were people with a learning disability. In response, digital connectivity projects for people with a learning disability were set up across the Cwm Taf Morgannwg region, with technology being gifted or loaned to those unable to connect through a range of different service providers.

Both Cwm Taf People First and People First Bridgend, embraced the call to not only help their members connect digitally through lockdown, but to have a valued voice that could shape decisions being made across the region that directly and indirectly affected them and their livelihoods. Funding was obtained to distribute tablets and laptops, and systems were established to help people share their experiences and have a voice on matters of interest. Through the regional Our Voice Matters project a series of online events were held titled Hear Our Voice in Lockdown, that brought together people with a learning disability, parents and carers, local authorities and other service providers to have open and honest conversations about current Covid-19 response measures and plans for the future. These events were a great success and developed a co-productive mechanism for people with a learning disability and their families to be informed and involved at both local and regional levels.

It was through this digital connectivity that the My Day My Way project team were able to meet and design the project activities in line with its co-productive approach. Some of the

engagement tools utilised for the project also relied heavily on the ability to connect with people virtually, but through the Easy Read Questionnaire, also acknowledged that not everybody was able to/ wanted to connect in this way and provided an alternative option for engagement.

Following an evaluation of the digital connectivity project, under the phase 1 activities of My Day My Way, recipients of an iPad/tablet/laptop reported an average 84% positive impact made on their lives during the Covid-19 pandemic lockdown periods, citing having the ability to connect with others as their main reason for this score. The majority of recipients identified that they had no issues when using the technology. For those that did acknowledge some difficulties, the main source of their issues was forgetting their passwords and having internet connection problems. Some of the recipients were unable to read, and this impacted their ability to engage in some virtual meetings and activities as they were unable to understand login emails containing Zoom and Teams codes. To combat some of these issues, the My Day My Way project has purchased Log Me In software that will help the project team remotely log members with an iPad/tablet/laptop that has been gifted to them through the People First digital connectivity project so that they can join in and be part of future conversations about things that matter to them.

The Log Me In software is quite complex and therefore through the projects phase 1 activities, has not yet been implemented fully. The project team have been undertaking the necessary training to use the software correctly and to its full capacity, working with the software developers to find the best way for the software to be used to meet the needs of people with a learning disability. It is anticipated that with further development and training, implementation of this software will happen through the projects phase 2 activities.

“Before lockdown I did have a laptop but not the software. Through the project I have now been able to meet new friends and learn new skills”

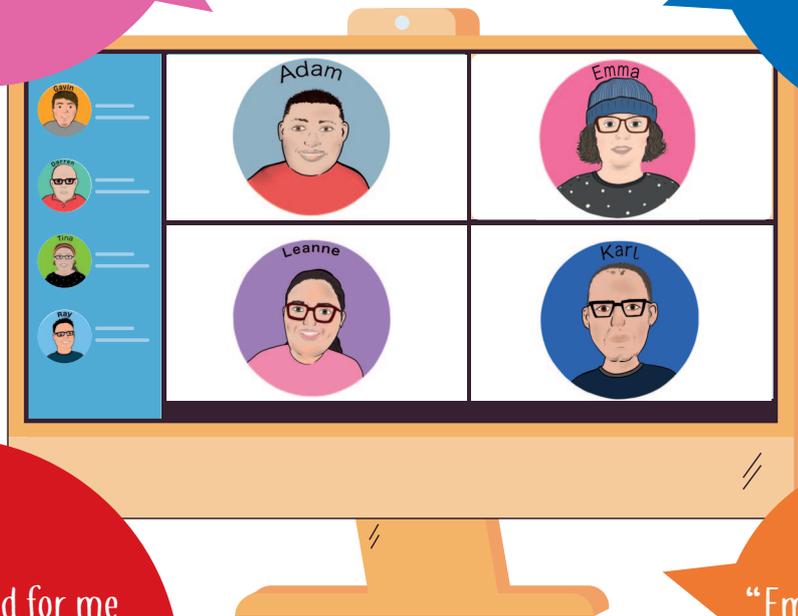
Rebecca, RCT

“This is my first time to have an iPad and now I can talk to you”

Becky, RCT

“The iPad can be hard to use sometimes, but I like it”

Bradley, Merthyr Tydfil



“It has been good for me as I have learned new ways to communicate”

Lynne, RCT

“Emails can be difficult because I can’t read”

Owain, RCT

“Having the iPad has made a lot of difference, now I have started to download games on my iPad. The graphics are brilliant and it makes a big difference”

Carl, RCT

“Someone from People First came to my door with an iPad and showed me how to use it. Sometimes I didn’t know what to do, now I do!”

Daniel, Merthyr Tydfil

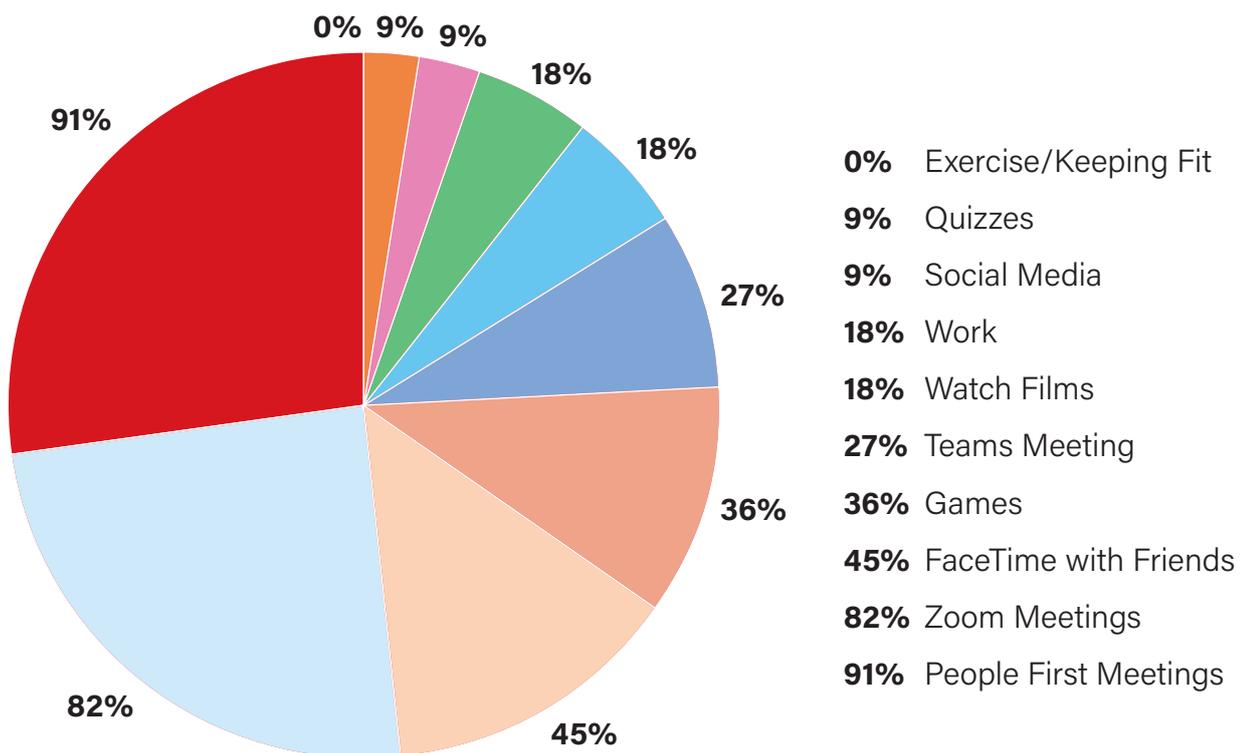
People with a learning disability have stated that they prefer to have meetings 'in person,' but they appreciate that this has not been possible during lockdown and therefore they have been very grateful for the opportunity to connect and have a voice virtually.

How People with a Learning Disability prefer to be engaged in meetings



- Cwm Taf People First have gifted 52 iPads across RCT and Merthyr Tydfil to ensure their members voices can be heard.
- People First Bridgend hold bi-weekly/weekly virtual Advisory Group meetings with their members to ensure their voices can be heard. Currently 7-10 members are involved in these meetings.
- 7 Hear Our Voice in Lockdown events have taken place since lockdown began March 2020-March 2021 with people’s voices being fed into and having impact at local, regional and national levels.

Activities that People with a Learning Disability have been able to do on the iPad



My Day My Way:

what is important to people with a learning disability in a post Covid-19 world

The majority (87%) of the people engaged in the My Day My Way project indicated that they would like to change something about their day as things move into a post covid-19 climate. What they would like to change was largely varied, the enclosed statistics reference the changes suggested where 2 or more people agreed. Overwhelmingly, people indicated that they would like to have more opportunities to meet new people, with many referencing that this is something they have enjoyed through the lockdown period by joining in activities and meetings digitally using their phones, tablets and laptops. However, it was also noted that this, for many, was not their preferred method of interaction and they are looking forward to being able to see people in 'real life' and not via a screen.

“I like doing different stuff and different kinds of activities with my friends. At the moment I go out in the car and take sandwiches and a flask. It is good to see new and different places”

Sam T. RCT

Similarly, when asked what would make a good day for them in the future, responses were largely diverse, reinforcing the need for person centred approaches to daytime activity design. However, the continued theme of being sociable and seeing and spending times with friends and family featured high. Especially through the interviews and storytelling elements of data collection, many people referred to travel as the key to allowing them to do the things that they would like to do,

including participating in community activities, visiting new places and going on holiday's within the UK and across the globe.

“I can't wait to go out with my friends for fun. I haven't seen much of them through lockdown so it will be good to meet up to see them”

Gavin, Bridgend

There was also a number of people who indicated that they were keen to return to their previous day centre provision, again with reference being made to missing their friends, the staff, and a structured routine. For others however, this break from the day centre cycle that Covid-19 and lockdown restrictions has brought, has allowed them to start to think and dream about alternative things they could do in the daytime, with many highlighting a desire to engage in some form of work or volunteering placement as part of their weekly activities.

What People with a Learning Disability said they would like to change about their day

- More meetings with People First **3%**
- Visiting different places **5%**
- Having a more structured routine **5%**
- Seeing new friends **7%**
- Try volunteering/employment **12%**
- Nothing **14%**
- The amount of time spent at their daytime activity **42%**
- try new things **46%**
- Meet new people **58%**

What I want life to be like after covid-19 and lockdown

Adam

- Holidays
- More volunteering with dogs trust as a dog Walker
- Really want a paid job so I can go shopping
- Go back to my fitness classes
- Go to see my mates
- Seeing pantomimes again
- Go back to work placement at the garden nursery

STACEY HARDING ILLUSTRATION

Leanne

- Have a birthday party
- Go to Disney World Florida
- A catering course
- Shopping trips
- Beauty and pampering (hair, makeup and nails)
- Getting qualifications is really important to me
- Go back to college

STACEY HARDING ILLUSTRATION

Tina

- Go back to Day Centre and see my old friends
- Make new friends in my area as I have moved home
- Be more independent - cooking - shopping - managing diary
- Go back to volunteering in a charity shop
- Work in a café
- I would like to try going to college
- If I get more independent I will need less staff support and enjoy time to myself and set my own bedtime

STACEY HARDING ILLUSTRATION

Ray

- Go to the pub for lunch
- A holiday somewhere hot with a glass of wine
- Using the library and reading books
- Arts and crafts
- Volunteer support work having a cup of tea with people and talk about their problems
- Wouldn't mind going back to daycentre
- Play darts/pool again
- Wouldn't mind doing hair and beauty

STACEY HARDING ILLUSTRATION

Conclusions

After reviewing all of the information collected through the projects phase 1 activities there are a number of key highlights that show not only the importance of meaningful and purposeful daytime activities for people with a learning disability, but that many of them are open and ready for change. The information shows that:

- the most important thing to people with a learning disability across the Cwm Taf Morgannwg region is social connection; spending time with friends, family and staff. This is something that they have missed and craved during the lockdown periods and is a focus for many as they consider what life will be like when they are able to re-engage in daytime activities in a post covid-19 climate.
- Whilst some people with a learning disability are looking forward to having a regular routine again once they are able to re-engage in their daytime activities, others have enjoyed the elements of flexibility that lockdown and the dis-engagement of their previous activities has provided. Being able to choose what they do on a daily/weekly basis is important, and many referenced wanting to see new places and try new things. Some also discussed wanting the ability to change their daytime activity if/when they want to, and not feeling stuck in one place. To do this they referenced needing to know the different options that are out there for people with a learning disability, and there was particular interest towards volunteering and paid employment.
- Gaining qualifications and learning new things is also important to people with a learning disability, and whilst discussion surrounding education was met with mixed feelings, many people with a learning disability suggested that they would like to try different courses that were not currently on offer to them, and that some wished they could stay in college longer. When analysed against some of the wider conversations and information gathered through the project, there may also be opportunities for expanding prospects in community-based education for people with a learning disability.
- Digital connectivity has provided a lifeline for people with a learning disability across the region over the past 12 months, and in particular through lockdown periods. However, not all people with a learning disability are able to or want to connect digitally and therefore, people with a learning disability have expressed that they like to have a range of different ways to engage in work and decisions, with most indicating that they prefer, and look forward to in the future, having meetings and being engaged face-to-face
- Employing people with a learning disability can be and should be done in a non-tokenistic manner, and they should be empowered through the implementation of sufficient support mechanisms to lead on the design, delivery, decision making and evaluation elements of the project.

Recommendations

Ultimately at the heart of all the information gathered is the need for a diverse range of daytime opportunities for people with a learning disability across the region so that they can have choice and control over what they do during the day. This needs to be accompanied with flexible person-centred plans being developed and regularly reviewed for individuals so that their right to choice and control is protected. To ensure that this is done effectively, further development of the projects work is needed to gain greater insight into how this can be achieved. As a result, the following recommendations are offered to help shape the projects phase 2 (and beyond) activities:

1. Continual development of new and innovative engagement tools to increase accessibility and participation within the projects co-production approach
2. Mapping of opportunities across the 3 local authority areas to identify a directory of local activities people with a learning disability can get involved in
3. Identify barriers associated with access to local opportunities, including travel, so that people with a learning disability feel confident to engage in them
4. Undertake further work to develop a regional employment campaign for people with a learning disability looking at:
 - i. the benefits of employing people with a learning disability
 - ii. further exploration of the therapeutic earnings level and the effect paid employment may have on people with a learning disability, positive and negative
 - iii. the development of a peer mentorship scheme for people with a learning disability to help them understand their duties and responsibilities as an employee and how they can further their career in the future
 - iv. development work with supported employment agencies and projects to ensure holistic learning and a collaborative approach to the promotion of employment opportunities for people with a learning disability
 - v. training development around money management
5. Further development and training of the Log Me In software to provide assistance and appropriate support to more people with a learning disability to engage in digital activities and have their voice heard
6. Dedicated work and exploration of day centre services across the region
7. Exploration of wider social, evening and leisure activities for people with a learning disability
8. Identify opportunities for friendship development and maintenance looking at ways for friendships to be considered and included in the design of individuals daytime activities
9. Opening up the conversations and work focus of the project to include the insight, thoughts and opinions of family members, support workers and service providers
10. Development of a regional working group to oversee local and regional plans related to daytime opportunities, led by people with a learning disability as experts by experience

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