







## The Perceived Barriers for Services, Professionals, Organisations and Projects

As part of the phase 1 research activities, the Our Voice Matters project also wanted to consider some of the issues and barriers experienced by the services, professionals, organisations and projects who are working with individuals with lived experiences as outlined in the above five categories. Whilst there was an appreciation for the barriers that have been expressed by the five above categories, additional factors were outlined by the individuals within this group. These additional factors had a more strategic feel to them and included things such as GDPR, Legislation and Funding. A lot of discussion was held about issues relating to funding, especially short-term or limited funding, and

how this impacts the sustainability of services and projects. Services, Professionals, Organisations and Projects have suggested that longer-term funding will help to make sustainable positive change by allowing them to understand individual needs and experiences in more detail, and therefore design and deliver services in a more co-produced and person-centred manner.

### COVID-19 Response

As part of its response to the COVID-19 pandemic, the Our Voice Matters project initiated its #CTMLockdownVoices campaign as part of its wider Hear Our Voice series. The campaign was purposely broad with little agenda other than to provide the citizens of Cwm Taf Morgannwg a mechanism in which to share their experiences and stories of lockdown. As information was fed into the campaign, the Our Voice Matters project was able to identify some clear emerging themes and escalate this information into wider research and decision-making processes.

Whilst citizen engagement with the campaign varied between the different identified groups a wealth of data was collected from a variety of different individuals and organisations supporting individuals to provide a good sense of citizen voice representation. The move to a virtual platform was not welcomed by all but for both people with learning disabilities and parent and carers, the virtual world appeared to increase access to engagement activities. Supported by funding to issue iPads to individuals to help them connect and reduce levels of loneliness and isolation, a key opportunity for vital virtual conversations to take place with both statutory and third sector service providers has been developed through the campaign, and people with lived experiences have not only been able to set the agenda but to facilitate conversation to ensure that their voices and experiences are being included in the future planning and shaping of services.

From data collected through the campaign and wider virtual engagement activities developed, the Our Voice Matters project has analysed the key emerging themes to establish a list of priority areas for each of the identified lived experience citizen groups, to allow a needs and experience driven response to future service development plans at both local and regional levels.

### Children and Young People

Prior to lockdown, the Our Voice Matters project, supported by InterLink, held a regional Children and Young People's engagement event that allowed those in attendance to express their thoughts and opinions through a range of participatory research activities. The information gathered at this event has been analysed against Children and Young People's engagement through the #CTMLockdownVoices campaign to identify the following priorities. The priorities are offered in no particular order:

#### 1. Resilience Building/ Mental Health and Wellbeing

- Bullying was identified as a key barriers/issue for children and young people and they would like to see more work being done to tackle bullying, increase respect for others and build and strengthen friendships and peer support networks.
- Mental health and wellbeing was expressed as a major issue for children and young people prior to lockdown, however this has intensified through lockdown due to a lack of social contact, lack of/changing routines and confinement. It has been highlighted that for some children and young people with additional needs, such as Autistic Spectrum Disorder the adverse effects of lockdown have been devastating and has left many families (not just the child or young person themselves) unable to transition back into and function effectively in society. Therefore, children and young people would like targeted support to help them overcome fear and anxiety associated with COVID-19 and lockdown, and to transition back into normal everyday living effectively.

*"We need more teaching of children and young people about how to look after our mental health"*

- Issues around gaining access to support and counselling services in a timely manner have also been raised by children and young people, with many often stating that they have to be at crisis point before they can get help. Equally, many highlighted that they didn't know where to go to get help if they needed it, especially during lockdown when they weren't at school. As a result, children and young people would like improved access to counselling services and mental health support, especially outside of the school environment which they can engage through lockdown or self-isolation periods.
- 'Confidence' and the lack thereof, was identified by children and young people as a barrier, with many stating that they couldn't do the things they wanted because they didn't have any confidence. They also suggested that a lack of confidence meant that many children and young people don't feel good about themselves and that this can lead to mental health issues like self-harm, anxiety and depression. Therefore, children and young People would like to

engage with more confidence building activities to help them do the things they want to and to view themselves in a more positive manner.

*“a lot of young people lack confidence to do thing, we need to change this!”*

## 2. Community Integration and Safe Places for Children and Young People

*“I want to be more valued in the community and to see what it is like for people who are homeless or have a disability etc. so that I can understand and help them”*

- From the data collected it is clear that children and young people would like opportunities to play an active role within their communities and to mix with community members of all ages and abilities. They are keen to learn about how to be a good citizen and to make the community a safe place for everyone.

*“More people need to talk about appropriate behaviour around the community so that we can help each other and break stereotypes/labels!”*

- Some young people feel their community is not a safe place for them because they will be judged negatively. They don't feel welcome or valued and this has an adverse effect on their mental health and wellbeing. They would therefore like to see places and spaces in the community designated as 'safe' and young people friendly where they know they can go for help and advice, or to spend time with friends in a judgement free environment.

*“Sometimes I don't know where I can go to meet or make friends in the community, I feel like I am not safe in some places if I am there or on my own or even with some friends”*

- Young people have also suggested that lockdown has shown them that there are good people in their communities and that their community is a good place to live. For those who receive free school meals, lockdown developed some anxiety for them and their parents around how and what they would eat, however, many suggested that they have had support from food banks, community centres, neighbours and community members and that this has really helped. Although this has not been the case for everyone, and young people have highlighted that they would like to see more opportunities for their community to 'come together' and take care of one another.

## 3. Aspirations, Careers and Opportunities

- Children and young people have expressed that the lockdown period has made them reflect on life and opportunities outside of school and in the future. Having opportunities taken away from them or moved to an online platform has helped them to realise just how important having activities and support can be and as lockdown ends they have expressed that they would like to see new/more opportunities being opened up to them that help them learn what they are good at, the things they like and don't like doing, to try new things and how to achieve their dreams.

*“lockdown has made me think outside the box about my future and what is important to me, now I just need to find a way to do those things that make me happy”*

*“more career opportunities are needed so that we can understand what options there are for us after school. More volunteering and work experience opportunities so we can try a career before we commit to it”*

#### 4. Communication and Information Sharing

- It was identified that the way the majority of young people accessed information relating to COVID-19 and other issues through the lockdown period was via social media, which provided them with a lot of false or misleading information. Young people expressed that they didn't really watch the news, and that they didn't know where else they could get information from. Some did say that they would ask their parents but still felt they didn't fully understand what was going on. They would like information to be communicated in a clear way that helps children and young people fully understand the truth and to be able to determine the difference between 'fake news' and reality, and to have easy access to reliable information.
- Young people also highlighted that they didn't know where to go to get information about other things outside of COVID-19 and the majority said they would turn to google for advice. Some young people highlighted that they had continued to engage with youth workers/project workers through lockdown and that this had also been a source of information for them. Some young people suggested that they preferred having this interaction on a virtual platform whilst others suggested that they felt they couldn't express themselves effectively on zoom or messenger.
- Technology has played a massive communication role through lockdown but for some young people this has become a huge barrier to engagement. Internet connectivity has proven to be problematic in some areas across the region, whilst others do not have access to suitable technology devices such as smart phones, tablets and computers, which has not only impacted their ability to engage but also their ability to effectively learn through the home schooling model. Therefore, children and young people would like better internet infrastructure across their communities and better access to technology to help them stay connected and able to participate in home schooling activities.
- Some young people noted that they have spent a lot of time online through lockdown, and although they felt they knew how to keep themselves safe online, they realised that some people in the community might not, leaving them vulnerable to scammers and groomers. They would like more work done to protect people online and teach people how to keep themselves safe online.

#### 5. Youth Voice – we want to be heard!

*“children and young people like us need to be taught about local issues so that we can contribute to solutions”*

- Making them feel valued, listened to, included and involved has been identified as a key priority for children and young people. Young people have expressed that they are often consulted but hardly ever receive any feedback, especially if their ideas cannot be fulfilled. It was also felt by some young people that decisions had already been made before they were consulted and therefore their opinions didn't really matter. Therefore, children and young

people would like to be fully involved in decision making processes and would like to be seen as an equal and valued contributor to decisions. In addition, they would like to be informed about the progress of consultations and decisions they are part of, and welcome regular feedback and justification when things cannot be achieved as they had suggested.

*“you need to meet with us before writing a draft so we can give you our ideas and views”*

*“people should ask us about what affects us!”*

*“we need people to feedback to us and tell us what is happening”*

## 6. Education and Life Skills

*“education in a more comfortable and supportive environment that helps us learn. I can struggle to get motivated to do my work at home, when I do it I learn more because I am relaxed and don’t have pressure from my friends”*

- Lockdown has allowed a lot of young people to reflect on the importance of education, as well as how school helps them to socialise and have crucial social contact with friends and peers. Many young people expressed how they were excited to return to school, however, for some this has caused increased anxiety and fear, with some children and young people indicating they want more mental health and wellbeing support to help them in school.
- Bullying was identified as a key barriers/issue for children and young people and some suggested that this was a reason for the anxiety and fear they were feeling about returning to school. This is because they felt that the majority of bullying they experienced either happened at school or on the way to or from school. They have outlined that resolving this issue is a key priority for them.
- Some young people identified how through the lockdown period they had learnt new skills either at home or through online videos and courses such as cooking and sign language. There is a desire for more opportunities for life skills learning to be made available to young people so that they feel better equipped for life and able to try different things.

*“I want more chances to do things and to learn things that I can use in life situations. Through lockdown I have done lots of cooking and I really enjoy it and I have been watching videos on social media of craft ideas and fitness and stuff like that”*

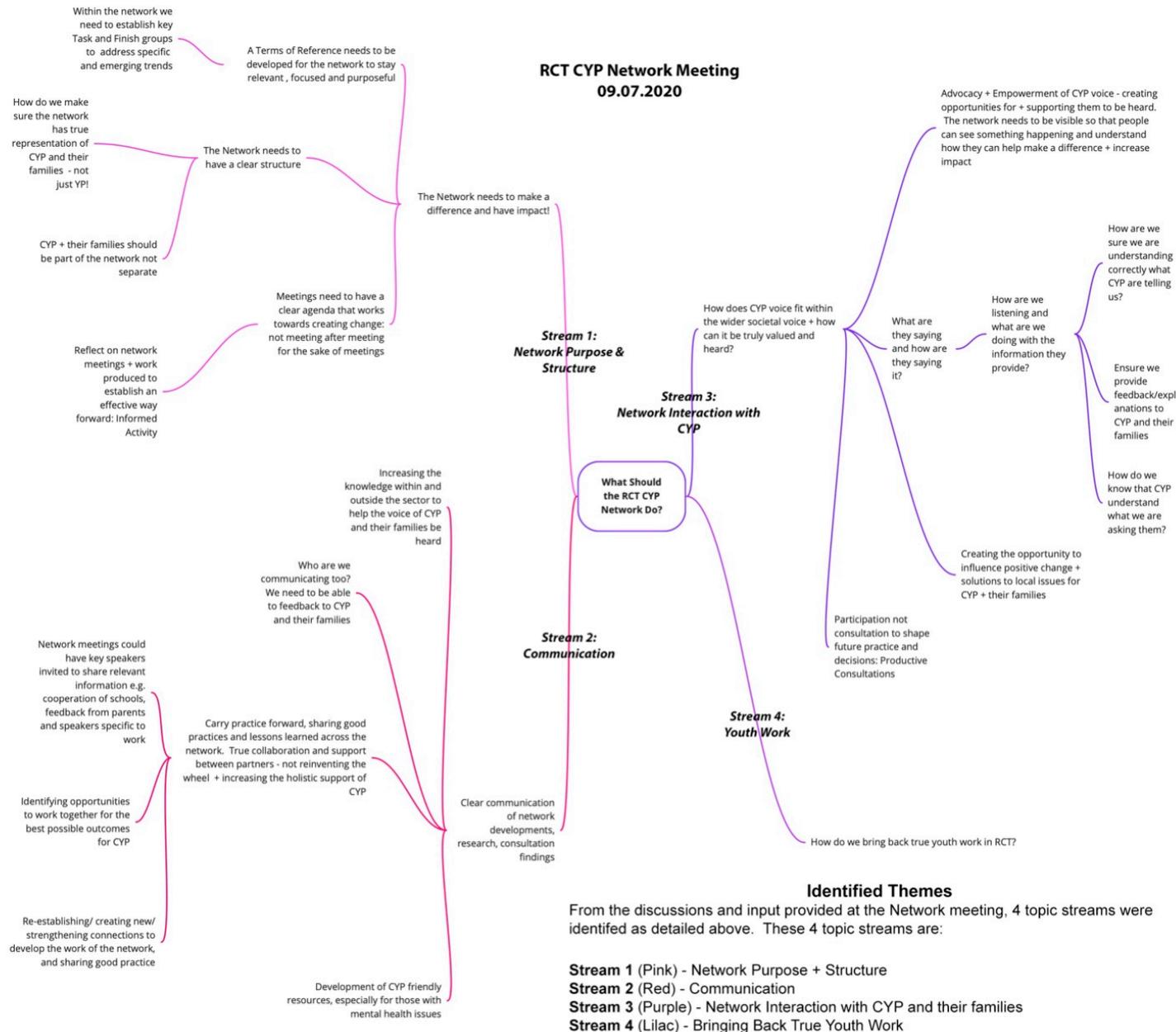
## 7. Friendships and Peer Support

*“we need help to find new friends and meet new people from in and outside our community when lockdown is over. Friends can help us stay happy and healthy”*

- The lockdown period has had a real negative effect on the friendships of some children and young people, especially those who have not had access to technology or internet to be able to connect with their friends in a virtual space. This has led to a lot of young people feeling isolated and alone, which in turn has had a negative impact on some young people’s mental health and wellbeing. Some young people have expressed that lockdown has made them appreciate their friends more and that they are planning to be a better friend

and not take people for granted as lockdown finishes and they return to school. Therefore, Children and Young People would like to support to make, sustain and strengthen friendships, allowing them to build better peer support networks to face future crisis situations.

In addition, a lot of work has been conducted through the lockdown period with organisations and projects who have been working to support children and young people to help increase understanding of the reality of lockdown for this group. Whilst some contact and engagement has happened with organisations and projects across the region, the majority of this has been central to Rhondda Cynon Taf through the creation of a pilot Children and Young People's professional network led by InterLink in conjunction with the Our Voice Matters project. This network was established in early July 2020 and the below diagram outlines the priorities that had been co-produced across the network to develop 4 distinct work streams to inform and focus its work over the coming months/year



## Learning Disabilities

Prior to and throughout lockdown, the Our Voice Matters project has been working closely with RCT People First, Cwm Taf People First and People First Bridgend to engage a wide range of people with learning disabilities through the #CTMLockdownVoices campaign. In addition, the project has been working with adult services from each of the local authority areas, as well as a range of service providers to facilitate specific and detailed conversations about emerging priorities for citizens with lived experiences in this category. Parents and carers of people with learning disabilities have been involved with some of these engagement and co-production activities to ensure a holistic perspective is considered in finding solutions to issues and developing service plans for a post-lockdown climate.

These conversations and engagement activities with people with learning disabilities has been made possible with the support of COVID relief and response funding given to RCT People First to supply its members with iPads. This has allowed virtual connection with people with learning disabilities throughout the lockdown period. The data that has been collected through these virtual engagement activities has been analysed alongside the pre-lockdown What Matters To Me work, conversations and workgroup action plans that have been led by people with learning disabilities across the region to assist in the identification of the following priorities. The priorities are offered in no particular order:

### 1. Communication and Information Sharing

- It has been highlighted by people with learning disabilities that information is not always accessible to them. This is not a new issue but one that has been intensified through lockdown due to the large amount of information being circulated in relation to COVID-19. Additionally, people with learning disabilities have felt that a lot of jargon has been used when people talk about the virus and this has caused a lot of confusion and fear. People with learning disabilities would like more Easy Read and accessible information made available to them in a timely manner so that they can feel informed. They would also like to know where they can go to get information.
- People with learning disabilities have suggested that prior to and during lockdown they have felt that a lot of choice has been taken away from them and they are told what to do. They would like to be included in decisions that affect them so that they can share their views and opinions. Some made reference to the online conversations that have taken place with the local authorities and wider service providers around the re-opening of day centre services and future day centre plans as a good example of when they have felt included and valued. They would like to be included in more conversations like this as they expressed they also learnt a lot about what is going on and why things are happening in a certain way, which has helped them to understand the actions of service providers.

*“We need information about what we can and can’t do and for people to include us when making these decisions”*

- People with learning disabilities have welcomed the opportunity to connect with people virtually during lockdown but can struggle with certain applications and meeting platforms. FaceTime and Zoom have been the

communication platform of choice for the majority of people with learning disabilities we have engaged with, however, this has appeared to have created a barrier for interaction with statutory sector who are restricted to the use of Microsoft Teams through corporate IT policies. As a result, some people with learning disabilities have felt like they are being dictated too and forced to adapt to be able to have their voices heard. Without intense training, delivered in person it has proven very difficult to engage people with learning disabilities on Microsoft Teams leading to gaps in representation. People with learning disabilities request that an effective communication platform is identified that meets their needs in terms of ease of use and accessibility so that they can continue to contribute to and inform the decision-making processes locally and regionally.

## 2. Daytime Opportunities Reform – My Day, My Way

- Lockdown and the closing of/decreasing capacity of daytime opportunities for people with learning disabilities has provided an opportunity to reflect on the effectiveness of day services across the region. As a result, most felt that the daytime opportunity they had previously been engaged in didn't fully meet their needs or satisfy their wants and desires. This was particularly evident for those who attend traditional day centre provisions. Therefore, people with learning disabilities would like to have more opportunities and choice regarding the daytime opportunity they engage, with particular focus on innovative employment/volunteering and education options that help people integrate in the community, as these were highlighted as a means to increase individuals self-worth and value, and reduce loneliness and isolation.
- Through the lockdown period there has been an evident decrease in the mental health and wellbeing of some people with learning disabilities as a result of increase loneliness and isolation, as well as fear and confusion. People with learning disabilities through their engagement with the Our Voice Matters project and their local People First organisation have recognised that this is a growing area of concern which needs to be addressed. Suggestions offered have focused on generating more opportunities for social contact both online and in person (within the prescribed COVID-19 guidelines) to help them establish support networks and helping people with learning disabilities connect with new activities, develop new skills and be more active especially in local outdoor spaces.

*“my way of getting out of my depression has been cooking to get me out of wanting to kill myself”*

## 3. Supported and Independent Living Guidelines Review

*“I am not happy about all these things around bubbles. When ‘the germ’ came I left supported living and went to stay with my family for a few months. Now lockdown is ending I have come back to my own home and now the staff are telling me I cannot do the things I want to like seeing my family”*

- The COVID-19 response and lockdown period has highlighted some inconsistencies and confusion around Supported and Independent Living. Some people with learning disabilities who live in supported or independent living accommodation have felt like they are being segregated and treated differently to their peers who do not live in such accommodation. This became particularly apparent in terms of the rules for people in supported and independent living not being allowed to form ‘family/social bubbles’ as an extended household when the wider population were able to do so, generating fear and anger. People with learning disabilities would like the guidelines for supported and independent living providers to allow/promote individualised risk assessments for tenants rather than implementation of generic measures, allowing people to have more ownership and choice over their lives.

#### 4. Transport

- Transport has been a key priority for people with learning disabilities for a long time now, and this has been escalated by some of the experiences people with learning disabilities have encountered through the COVID-19/lockdown period. Through recent engagement activities, people with learning disabilities have highlighted that:
  - Reduced timetables through lockdown have meant they can’t get out and about and have encountered issues in attending some scheduled appointments, especially with health services. For some this hasn’t just been an issue through COVID, but their usual public transport service doesn’t allow them to attend appointments early in the morning and later in the afternoon. Therefore, people with learning disabilities would like a review of public transport timetables (in particular bus timetables) to be undertaken to give them the flexibility to attend regular appointments between 8am – 6pm.
  - There is a need for accessible timetables for public transport services. Many people with learning disabilities indicated that they find it hard to understand the timetables, and that the print is too small. They also outlined that they can experience issues with the current time format that is used. Therefore, people with learning disabilities would like timetables to be converted into an Easy Read format that uses visual aids to help them understand the prescribed time.
  - Many people have experienced negative attitudes towards them when using public transport. This can be from transport staff and drivers or from other members of the public. These negative attitudes have made some people feel uncomfortable when using public transport and increased their isolation due to fear of potential negativity towards them. As a result, people with learning disabilities would like public transport staff and drivers to undergo learning disability awareness training to help them understand and support people with a learning disability better when they are accessing their service.

*“I had a really bad experience with a bus driver and my husband. The bus driver didn’t have patience and was very rude to us. No one had masks on on the bus”*

*“Bus drivers need to have learning disability training – if we train them things that have happened to me in the past might not happen again. We have done training like this with the police and nurses so we should definitely do it with bus drivers”*

- Travel training for people with a learning disability was flagged as important and people with learning disabilities would like to see more travel training and travel support being offered across the region.

*“Just before the pandemic my son started a travel training programme and now that has been put on hold and will set him back a lot”*

## 5. Friendships and Peer Support – social contact and leisure activities

*“The lockdown is a barrier because we couldn’t go out and see friends. It has made me depressed when I can’t see my friends and sometimes I just feel like I have been forgotten”*

- Friendships and in some case the idea of a friendship has become a clear emerging priority for people with learning disabilities through this COVID-19/lockdown period. Whilst some individuals reported that they felt they had never had a friend, others indicated that they thought they had lots of friends; however, these were all either paid workers/staff or people they attend day centre with. As lockdown brought a closure or imposed restrictions on day centre services across the region, many people with learning disabilities began to experience new levels of loneliness and isolation, and as a result, they have highlighted that they would like to make ‘real’ friends who can be there for them in hard times like lockdown.

*“all my friends are from day centre. Outside people find it hard to talk to us. The pandemic has made things harder as we have not been seeing staff and friends from day centre”*

- The funding secured by RCT People First to purchase and issue iPads to people with learning disabilities through lockdown has become a lifeline to recipients. They have highlighted how they have enjoyed being able to connect with people and meet new people safely from other geographical areas, and this is something they would like to continue/expand even after lockdown has finished. They did feel that this shouldn’t replace face-to-face meetings with friends, and that after lockdown they would also like to be supported to meet up with friends locally and from other areas safely within the guidelines.

*“we need more opportunities for social activities – Ffion has been doing the quiz night every Thursday on zoom, and everyone enjoys the chance to be social even though we are locked in. It is important that these kind of things still happen after lockdown so that we can spend time with our friends”*

- Prior to lockdown, some people with learning disabilities felt they couldn’t enjoy some social/leisure activities because they were restricted by staff schedules which meant they had to be in their homes/bedrooms by a

particular time. Moving forward they would like to be able to participate in a range of leisure activities without such restrictions.

## 6. Community Integration and Regional Safe Places Scheme

- People with learning disabilities have suggested that they don't fully feel part of the communities in which they live in and would like more opportunities outside day services to do things and be seen in the community. They expressed that they can sometimes experience negative attitudes towards them when out in the community and this make it feel like an unsafe place for them to be in. They also suggested that lots of people in the community underestimate what they can actually do because they don't have a full or good understanding of learning disabilities. This can leave people with learning disabilities being excluded from some community-based activities.
- People with learning disabilities have outlined that when they are out in the community and they need help they don't always know where they can go. Research has been conducted by the regional People First organisations along with some of their members into the national Safe Places scheme, that aims to train community organisations and business to become 'safe places' for any member of the community to seek help and assistance when needed. People with learning disabilities have agreed that they would like to see a scheme like this across Cwm Taf Morgannwg as it would help them to feel more confident and comfortable being in their community, as well as visiting other places across the region when lockdown restrictions have been lifted and it is safe to do so.
- Moving forward, people with learning disabilities would like more daytime opportunities that are based in their community. Some individuals have expressed that want to feel more useful and to help out in their community but that they don't know how to or would need some support to do this effectively. They feel this would help to break down some of the barriers they face in the community and remove the stereotypes and labels that they feel are placed on them.

## 7. Advocacy, Rights and Equality

- To further breakdown the barriers and stereotypes that people with learning disabilities experience within the community, work has commenced to create a regional Learning Disability Charter through the People First organisations. The charter aims to outline the rights and responsibilities of people with learning disabilities, community organisations, service providers and business so that they can work together effectively to co-produce services. The charter will encourage organisations, service providers and businesses to promote aspects of Voice, Choice and Control so that people with learning disabilities can be actively involved in decisions being made that affect them, allowing them to have some ownership over their lives. Community organisations, service providers and businesses will be asked to sign a commitment to the charter and suitably qualified people with learning disabilities will be tasked as charter checkers to ensure those who sign up to the charter meet and evidence the prescribed criteria. People with learning disabilities from across the region

would like to see the charter developed, co-produced and implemented effectively across the region to help them have a voice.

- To compliment the work of the Learning Disability Charter, people with learning disabilities would like to develop a regional Self Advocacy Strategy to make sure that others understand the importance of Self Advocacy and the role it plays in making sure that people with learning disabilities have voice, choice and control over their lives under the strapline 'Nothing about us, without us'. Some work has already been started via the regional What Matters to Me conversations and workgroups that were established prior to lockdown, but people with learning disabilities would like to see that this work is protected through the Self Advocacy Strategy.
- To promote equality within the community, people with learning disabilities would like to see more Disability Equality Awareness Training being delivered to a range of community members. This will help them to feel like equals within their community, but also develop some community based support mechanisms to help people with learning disabilities engage in community programmes effectively.

### Parents and Carers

Prior to and throughout lockdown the Our Voice Matters project has been working closely with The Grapevine to provide a platform for the voices of parents and carers of people with learning disabilities to be heard, ensuring they are involved in decisions that affect them and the person they are caring for. Whilst The Grapevine has provided the project with good parent and carer representation across RCT, and some representation across Merthyr Tydfil, representation for the group in Bridgend has been notably limited and identified as a gap for future development. Equally, limited engagement has been held with parents and carers outside of the learning disability demographic, and the project is looking to further develop its work with a wider range of parents and carers moving forward, in particular those caring for someone with Dementia.

The project also recognises the valuable contribution of young carers and has been working closely with Barnardos Young Carers project to understand the issues that affect this group to establish any common themes with adult parents and carers. Data collected from young carers was also fed into the Children and Young People's analysis through their attendance and representation at some of the regional events that have taken place.

The below priorities have been identified through a combination of analysis of data collected prior to lockdown and through engagement activities during lockdown. This has included online discussions held with people with learning disabilities, local authorities and service providers as part of the #CTMLockdownVoices campaign and Hear Our Voice series. The priorities are offered in no particular order:

#### 1. Respite Care

- Parents and Carers in RCT have been working with Rhondda Cynon Taf County Borough Council (RCTCBC) to make improvements to respite care services.

This has included work regarding the booking processes for respite care, from which prior to lockdown the successful implementation of improvements/recommendations had been made. The lockdown period has highlighted just how important respite care is and as a result, parents and carers would like a review of respite care services across the region to see how these can be delivered effectively in line with COVID related safety guidelines to ensure that parents and carers can receive adequate support through respite.

## 2. Greater Recognition and Support for Unpaid Carers

- Through COVID-19 and the lockdown period many parents and carers found themselves in a position whereby they had to take on full time caring duties for a loved one. Whilst parents and carers were happy to do this, as the lockdown period lengthened some started to struggle under the strain of these responsibilities. In some cases, their loved one required 24hour support, and without access to outside paid carer support or respite, many parents and carers started to experience burnout. Many of the people receiving care, or the parent/carer themselves were also on the shielding list and therefore found lockdown a very isolating period of time. This has had a drastic negative impact on some parents and carers mental wellbeing. Therefore, parents and carers would like a review of local authorities COVID response measures to identify how greater recognition and support can be provided to parents and carers if any future restrictions such as lockdown are imposed. Additionally, parents and carers would like to review the support package that was on offer to them prior to lockdown and to work with local authorities to identify where and how improvements can be made in a post lockdown climate.

*"I feel so sad for my sister, she has deteriorated drastically [in lockdown] and I fear she will never recover from this. She is stuck in a virtual prison and I feel sad for her. We have been totally abandoned. If we all die, I don't think anyone would even notice. My sister has suffered terribly and now this has happened she doesn't want to go back to day centre. She could walk before but now she can't and she is losing her ability in other ways. We struggled so much without carers, but since they started to come back in [my sister] brightened up a bit immediately. They are brilliant and she has missed them so much."*

## 3. Carer's Assessments

- Prior to lockdown, some parents and carers had been working with RCTCBC to review the effectiveness of Carer's Assessments, highlighting the following issues/ areas of concern:
  - That some parents and carers were not receiving assessments in a timely manner and that their appeared to be some inconsistencies regarding the delivery of these assessments.
  - That not all of the questions within the carer's assessment were relevant or worded adequately, and that there was a sense that the assessment didn't cover all areas important to parents and carers.

- That there was a lack of information within the assessment process about carers projects and where parents and carers could go for support.

Therefore, parents and carers would like to be involved in future work concerning carer's assessments across the region to ensure that they are effective and provide the desired outcomes and access to help, guidance and support parents and carers need.

#### 4. Social Worker Allocation / Changes to the Social Work Team

- Parents and carers from The Grapevine have been working with RCTCBC to review the effectiveness of the Social Work team and propose changes for improvement. However, progress has been incredibly slow in regard to any changes being made and this has made some parents and carers feel undervalued whilst leaving them without sufficient support. Some of the issues that have previously been raised are:
  - That many individuals don't have a single point of contact when requiring help or when experiencing crisis and therefore have to make contact via the duty desk. This often means that social workers who are unfamiliar with an individual's or family's history have to pick up the enquiry, and that users of service often end up repeating information to try and bring social workers 'up to speed' with their situation. Parents and carers feel this is ineffective and that this current system does not allow them and the loved ones they care for to develop a sense of trust with the Social Work team.
  - Parents and carers have also reported that they are often passed 'from pillar to post' when trying to find the correct place, department, team or individual to help provide them with the support they need.

Therefore, parents and carers would like to work with local authorities to review the current Social Work team processes and where applicable across the region, Social Worker allocation processes to help identify solutions for improvements. Additionally, they would like to see action taken on consultation and conversations they have been engaged in around topics such as changes to the social work team, as it is recognised that a lack of progress/momentum around implementing such changes has caused some feelings of apathy and de-valuing to the co-production process.

#### 5. Supported and Independent Living Guidelines Review

- The COVID-19 response and lockdown period has highlighted some inconsistencies and confusion around Supported and Independent Living. Some parents and carers who have family members who live in supported or independent living accommodation have felt like there has been stricter rules imposed on them because of their living situation, resulting in some parents and carers being unable to take their family member on holiday (within the UK) or for an overnight stay at their house, once lockdown restrictions had been lifted within the parameters of an extended bubble. Whilst parents and carers appreciate that supported living providers have an obligation to reduce risk to their tenants, a lot found it difficult to accept and understand why family

contact as an extended bubble was not permitted following wider population lockdown restrictions being lifted. Therefore, parents and carers would like the guidelines for supported and independent living providers to be reviewed and to allow/promote individualised risk assessments for tenants rather than implementation of generic measures, allowing people to re-connect with family.

## 6. Communication and Information Sharing

- As with the rest of the country, if not the world, lockdown has meant a move to a virtual platform for parents and carers to be able to communicate with each other and with service providers, and for some this move has not been a bad thing! Following a review of the barriers and challenges faced by parents and carers to engage in co-production activities, the top answer related to time and the simple fact that for many they were just too busy caring. Therefore, with more opportunities opening up virtually, this has allowed some parents and carers the ability to participate and have their voice heard. However, for others both technology and internet connectivity has become a new barrier resulting in their dis-engagement. Parents and carers would like the communication strategies used with parents and carers through lockdown and beyond to be reviewed and for greater support to be offered to help them connect virtually and in other ways, with suggestions around befriending services and the development and strengthen of peer support networks such as The Grapevine.
- Parents and carers have also noted that information that has been communicated throughout the COVID-19 pandemic and lockdown has been confusing and, in some cases, issued too late. It was noted that this was also the case for some information prior to lockdown and that there was and continues to be accessibility issues regarding information. This means that often the information they require is out there, but that a lot of parents and carers do not know how to access it. Therefore, parents and carers would like to identify a regional informational platform for parents and carers to access information that is relevant to them, in a way they can understand to bring clarity and reduce confusion.

*“We haven’t really had any support during this time, and we don’t know who to ask about getting support. In the future this information needs to be shared better so we don’t feel like we have been forgotten about or that we have to go out and do our shopping when we should be shielding.”*

## 7. Support and Opportunities for Young Carers

- The first priority that has been identified for young carers is the protection of their mental health and wellbeing. Being a young carer can be tough, and lockdown has made it harder for some as they have had to take on additional caring duties without their usual support mechanisms in place. Whilst service providers have tried to continue support virtually this has been difficult and as a result there has been a negative impact on the mental health and wellbeing of some young carers. Young carers would like to see more support programs

in place to help them look after themselves, physically and emotionally, so that they can look after the loved one they are caring for.

*“Within lockdown there have been so many emotions with me but I don’t like showing my emotions”*

- Being at home all day through lockdown has meant that young carers have experienced no respite from their caring duties. Not being able to attend school and not having the opportunity to attend ‘me time’ groups and sessions has increased the pressure placed on young carers. Many have linked into online activities to help them focus on something outside their caring duties however, young carers have reported that this is difficult because they don’t actually get to leave the house and therefore it doesn’t feel like a break. Some young carers have also outlined how lockdown has been difficult for them to do things like shopping and have provided positive feedback around how community-based services such as foodbanks have really helped them to survive. Now that lockdown restrictions are reducing, young carers want to see more opportunities for them to take some time out through respite care services and ‘me time’ style opportunities for them to engage with, and to find ways for them to interact with their local communities more as a source of support.
- Even prior to lockdown, young carers reported how they found it hard to make and sustain friendships as many other young people didn’t understand the responsibilities they had as a carer, and this put strain on their friendships as they often had to cancel plans last minute or were unable to attend events. Therefore, young carers would like to find ways to increase peer understanding of young carer identities, as well as identify ways in which they can make friends and create peer support networks to help them.

## Older People

Older people is one of the target group areas that the Our Voice Matters project has had engagement with through lockdown. However, prior to lockdown the project had brought together ICF funded projects under the older people category and held a number of meetings and events that included older people project representation as well as older people citizen representation to build the foundations of the priorities presented here. To try and establish the relevancy of these priorities in a post lockdown climate, the Our Voice Matters project has used the limited information provided by older people as part of the #CTMLockdownVoices campaign alongside conversations with the Health and Wellbeing and Active Inclusion Coordinators from Arts Factory to understand the emerging themes they have identified through their interaction with citizens through the lockdown period. The priorities are offered in no particular order:

### 1. Reducing Loneliness and Isolation

- Loneliness and isolation was an issue for many older people prior to lockdown, but with the lockdown, and for many in this category, shielding measures put in place, this was highlighted as a real concern for many. Through the lockdown period it was also identified by service providers that many older people are not online, and virtual engagement for people in this category was

inaccessible for a variety of reasons. For older people themselves, not being able to connect virtually meant that they lost touch with the outside world and found it difficult to access relevant and current information about the pandemic and the ongoing changes to restrictions. As a result, the following three areas of consideration have been proposed to meet this priority:

- Increase in telephone and face-to-face (within the COVID-19 safety guidelines) befriending services, to allow older people to create a support system for their mental wellbeing, and as a source to gather important information, help and guidance.
- Develop support and training opportunities to get older people connected virtually online, and to help them understand how to stay safe online from scammers.
- To identify avenues for more community and neighbourhood support, so that older people feel that they can access support and advice, as well enjoy a 'friendly chat' with people in their immediate locality.
- As lockdown ends, to identify and protect safe places for older people to go where they can be assisted in the community of needed. Prior to lockdown some older people highlighted that at certain times of the day or in certain places within their community they felt unsafe and wanted to feel like there were places they could go for a cup of coffee and a chat, or to meet new people without the fear surrounding accessibility issues and a lack of empathy if they required assistance.

## 2. Feeling Forgotten

- From the engagement had with older people, one of the reoccurring themes that gets highlighted by them is a sense of 'feeling forgotten' and becoming a burden to society. Especially for those older people who have good physical and/or mental ability, there is a feeling that the younger generations don't appreciate the knowledge and wisdom that they have gained over the years, and that there is an under-utilisation of their skills and expertise within the local community. Older people would like to feel useful in and to their local communities and would like to see more opportunities for them to participate in community activities, and to engage in intergenerational projects with younger generations. One suggestion offered in relation to this was a mentoring programme to help young professionals in a similar career to the one an older person had retired from.

## 3. Communication and Information Sharing

- Older people who have engaged with the project through lockdown have suggested that not only has not being able to access the new virtual world and way of living the wider population has seemed to embrace, but that their lack of online presence means that they often miss information. Some older people made reference to social media, and indicated that although they have access to the internet and have used things like Zoom to keep in touch with family members etc. that they miss out on a lot of vital information because it is on Facebook and that they don't have and don't want an account. Therefore, some older people have requested that information is shared via

post, and that postal and telephone services are used for some engagement activities to find out what matters to them and what issues they are experiencing.

- Further issues around this new virtual world were also highlighted in regards to GP and health services, and some older people have found it difficult to communicate their issues to the GP via the telephone appointment systems, and that if the doctor has asked to video call or for them to send a photograph this has become a barrier. For others in this category, the fear and anxiety of not being able to see a GP in person has stopped them making an appointment that they would have done prior to COVID-19 and lockdown. Equally issues were flagged surrounding prescriptions and accessing medication whilst shielding. Therefore, some older people would like there to be more options and greater support from health care services, GP practices and pharmacies so that they can access the health care and medications they need without the fear and anxiety of having to use online systems.

#### 4. Mental Health and Wellbeing

- As a result of the ongoing adverse effects of loneliness and isolation and the further issues COVID-19 and lockdown have created, the mental health and wellbeing of older people has been put at risk. In our engagement with older people they have often placed negative labels upon themselves such as a burden, useless, afraid and weak. Additionally, older people have referred to increased sadness as they experience a greater level of death and grief, and that for those (especially female widows) who had lost a spouse, they struggled find new ways to integrate in the community, and in some extreme cases have struggled to do even simple tasks such as shopping through fear or inability to cope on their own, or even how to get there and back without their spouse. Older people have suggested that they would like to see more programmes that help them to enjoy life and overcome some of negative barriers they experience in relation to their mental health and wellbeing, and to help them discover and try new things and meet new people. One group of older people prior to lockdown stated they wanted a way to go out with a bang and finish life well.

#### 5. Transport

- As for some other vulnerable groups within our communities, transport has been highlighted as an issue for some older people. Bus timetables appears to be a particular issue, especially in some areas of the region, along with the location of bus stops. Older people recognise that to maintain their independence and to be able to get out and enjoy life they need to be able to access a good public transport system that works in favour of their needs. Prior to lockdown, some older people had suggested that they were reluctant to take part in any evening activities as there was not suitable transport to get them there and back, and that even if there was that they didn't feel safe using public transport at night. Therefore, older people would like a review of bus and train timetables across the region, and for projects putting on activities for

older people to attend (when safe to do so) to consider public transport capabilities during their planning.

### People accessing Mental Health Services

People accessing mental health services appears to be the group with the lowest engagement rates with the Our Voice Matters project, yet mental health and wellbeing features as a key priority amongst all other target group areas. Whilst some limited engagement has been had with users of mental health services and mental health focused service providers both prior to and during lockdown, the priorities presented below have been lifted from wider interaction with citizens of all demographics that have made some inference to mental health and wellbeing. The priorities are offered in no particular order:

#### 1. Improving Mental Health and Wellbeing

- Through conversations and engagement with citizens from a range of target group areas, there has been a consistent recognition that many people in the community are struggling with their own mental health and wellbeing and that this has been made even worse by COVID-19 and the lockdown measures. Through lockdown many people have suggested that there has been increased levels of fear and anxiety for many and that especially for those who have been shielding, the lack of social contact has had a distinct adverse effect on people's mental health and wellbeing, and their ability to cope with simple everyday tasks. Citizens have also highlighted that there have been a number of people who have lost employment through lockdown and that some people are finding it hard to cope in new life situations/circumstances such as unemployment and navigating the benefits system for universal credits. Therefore, citizens would like to see a clear mental health and wellbeing support programme/strategy put in place as a response to COVID-19 that helps people to overcome any issues related to fear, anxiety, depression and hopelessness that they may have developed through lockdown. Equally, citizens would like to see increased information regarding support and advice, especially on a local level within their communities.

#### 2. Lack of Services/ Access to Services

- One of the key issues that is consistently raised by citizens in relation to mental health services is that they cannot get an appointment or the help and advice they need, when they need it. Citizens have reported long waiting times for services such as counselling and other talking based therapies and have suggested that your mental health needs to be so bad that you are at crisis point before you can access the help that you need. Therefore, citizens would like to see more services and appointments available for people suffering from mental health issues, so that they can obtain help and treatment at the earliest intervention opportunity.

#### 3. Resilience and Capacity Building

- There has been a broad discussion through the engagement activities prior to and throughout lockdown about preventative work to help people maintain

good mental health and wellbeing through educating people about how to look after themselves and how to keep themselves active. Citizens would like to see more preventative services that increase the resilience and capacity capabilities of citizens within their communities, and more positive messages to be circulated about what people can do rather than what people can't do.

As lockdown restriction ease, and the online engagement capabilities of citizens increases, the Our Voice Matters project aims to continue the exploration of citizen priorities and the perceived effects of the COVID-19 pandemic and national lockdown periods with individuals and service providers working across each of the highlighted target group areas. With the region now entering local lockdown restrictions, the project is interested in identifying if the above outlined priorities remain the same or if new priorities will emerge as a result of citizen experiences. As the project receives new data through its engagement activities, ongoing analysis against the above priorities will be undertaken and any changes reported into the relevant decision making bodies within the Cwm Taf Morgannwg Regional Partnership Board.