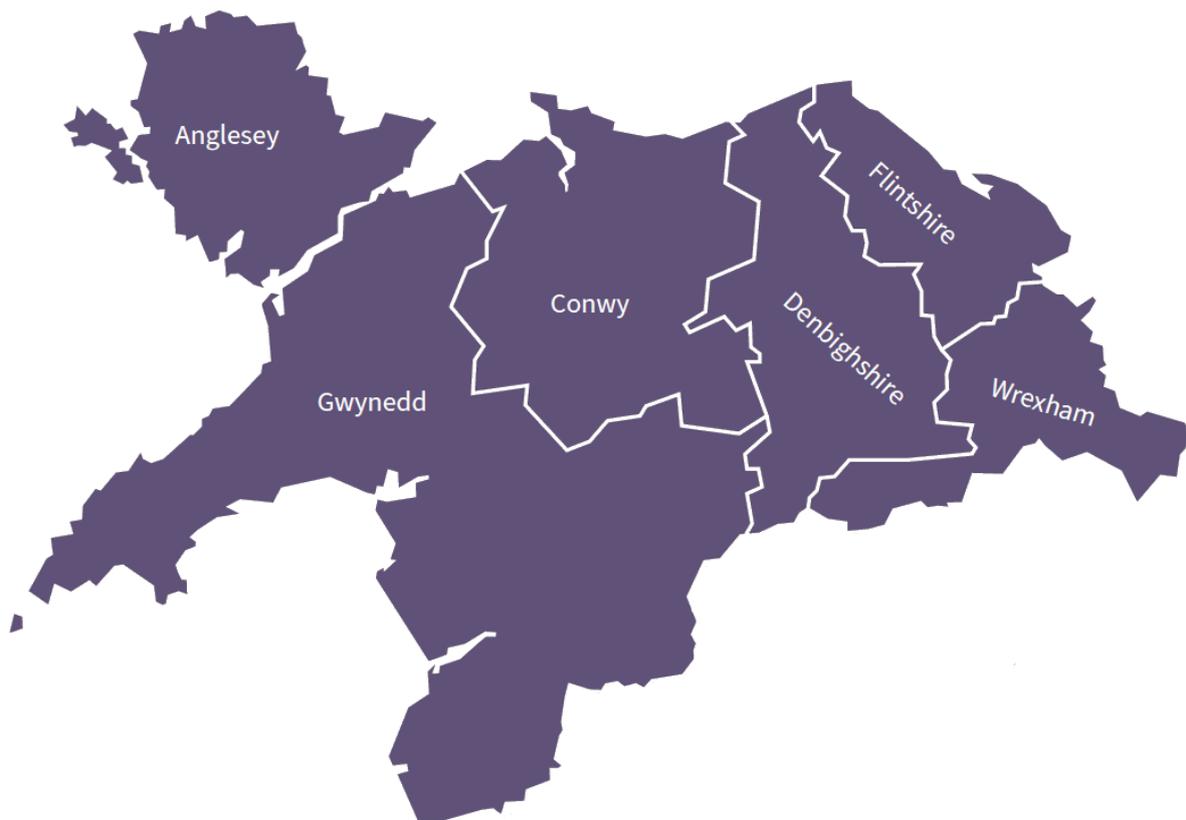




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**NORTH WALES** SOCIAL CARE AND WELL-BEING  
SERVICES IMPROVEMENT COLLABORATIVE

# North Wales Population Needs Assessment Rapid Review



**October 2020**

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# Introduction

Welsh Government asked Regional Partnership Boards to carry out a rapid review of the Population Needs Assessment originally published in 2017. The review summarises the available research about the impact of COVID-19 on people who receive care and support and changes to the way these services have been delivered. The North Wales Regional Partnership Board (NWRPB) will use the information from this rapid review to inform its winter plans and recovery and reconstruction work.

The original population needs assessment was produced along with people who use services and people who provide services. This approach has had to be adapted to a lighter-touch approach to take account of the short timescales for the review. The review involved a literature search of the impact on each group and includes findings from the COVID-19 innovations and lessons learned report (North Wales Research, Innovation and Improvement Hub, 2020). This includes findings from consultation and engagement undertaken as part of other related projects. It also includes a selection of stories gathered as part of our 'Most Significant Change' interviews, which we will share more about in a future report. The conclusions of this review can then be checked and reviewed as part of the population assessment update due to take place during 2021 to be published in March 2022.

## Summary

### Key themes

#### Equality and human rights

The coronavirus pandemic has highlighted and exacerbated many existing inequalities in society, such as the disproportionate impact on protected groups including Black, Asian and Ethnic Minority (BAME) people, older people and disabled children, young people and adults.

There has been an impact on human rights and the rights of protected groups, particularly people receiving care and support, those who have been 'shielding' and children's rights to play. There have been concerns around Deprivation of Liberties (DoLS) particularly for people living in care homes and for people with learning disabilities living in shared accommodation. While well intended, these practices

could have significant impacts on the liberty and relationships and be detrimental to people's health and well-being.

There are also concerns about the impact on the use of the Welsh language, including availability of guidance and community activities in Welsh, as well as a reduction in the number of bilingual meetings as services have moved online.

## **Remote working and virtual meetings**

These were used across all priority areas for business continuity and as a way of continuing to deliver some services. Staff say this generally works well and has brought forward changes that needed to happen. There is a lot less travelling and some services are now more efficient. Working from home was the change that people most wanted to keep. However, remote working has been challenging for some staff, particularly those who live alone or who have caring responsibilities. As well as the lack of peer support and opportunities for de-briefs on difficult cases and incidents.

Many services found online delivery worked well and made services more accessible for many people. The Covid Conversations survey found that 76% of people who had experienced a phone or video consultation found it a positive experience.

“A very good system that should be continued after the pandemic”

“Quick and easy. None of the usual lengthy delays waiting in a doctor's surgery”

However, 24% did not have a good experience. Some people who use services have struggled with the technology, online services are less accessible for some people, some miss the human contact and there is an increasing digital divide.

“Not personal, unable to read the person's body language or facial expression”.

“Very difficult trying to explain to a GP over the phone how I am feeling with multiple symptoms.”

The increasing reliance on digital technology for meetings, service delivery and helping people stay in touch with friends and family has identified the need for more training and support for care workers in how to support the people they care for to use technology.

Participants suggested taking a blended approach to virtual service delivery in future, so face to face options are available where necessary, with research and evaluation

needed to make sure that the virtual approaches are meeting people's needs and working to achieve what matters to people.

## **Communication, information and advice**

Many organisations increased the frequency of communication and pulled together resources for members of the public and people who use their services. Examples included a website of community resources, lists of local food delivery providers and emergency contact details. There were issues initially with large amounts of guidance and a lack of consistent advice, particularly relating to infection control procedures and Personal Protective Equipment (PPE) in care homes. While easy read guidance and videos have been helpful for people with learning disabilities, the production of materials has not always been timely and circulation of materials has been patchy.

## **Flexible and adaptable workforce**

Staff worked flexibly and quickly adapted to the new ways of working, including redeployment to different roles, changes in shift patterns and office hours, and providing weekend cover. There are concerns about the sustainability of this in the long-term and the risk of burn out.

## **Integrated working and faster decision making**

Many staff spoke about how integrated working improved between different agencies and professions in response to the crisis and that key decisions were made much more quickly than normal.

## **Mental health**

For all groups there is an emerging mental health crisis as a result of the pandemic and the steps taken to control the spread of the virus. This will be exacerbated by future lockdowns as well as job losses, increases in unemployment and poverty due to the wider socio-economic impacts of the virus.

## **Priorities and principles**

The review supported the continued work on the Regional Partnership Board priorities:

- Older people with complex needs and long term conditions, including dementia

- People with learning disabilities
- Carers, including young carers
- Children and young people
- Mental health

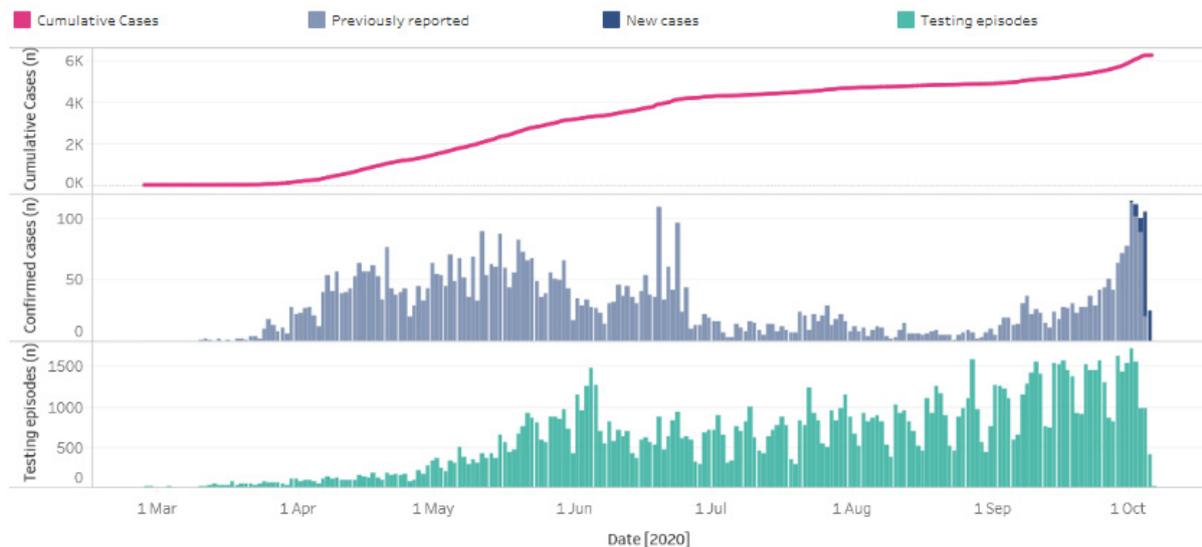
The review also identified the following principles based on lessons learned from the pandemic, which should inform future work on these priorities.

1. **Promote digital inclusion.** This includes making sure people who use and provide services have access to technology and connectivity along with the skills to use it.
2. **Inclusive approaches to service redesign.** While there have been many benefits to remote working and increased use of technology during the pandemic, these approaches do not work for everyone nor do they work in all circumstances. As services adopt new ways of working, they need to be carefully evaluated to identify and mitigate any potential harm. For example, by taking a blended approach to service delivery to maximise the benefits of virtual and face to face approaches.
3. **Take a rights-based approach** to future lockdowns and reopening of services to mitigate harm caused by policies designed to control the spread of the virus. This must include involving people who use services in co-producing policy and response and having voice and control in their own lives.

# Overview of COVID-19 in North Wales

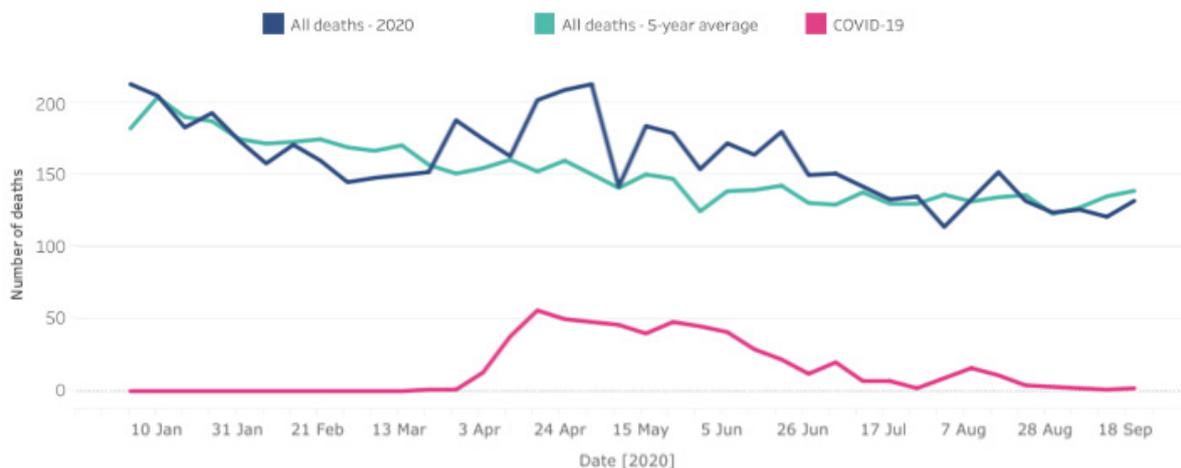
By 6 October 2020 there had been around 6,200 confirmed cases of COVID-19 in North Wales, or 1,300 for each 100,000 people in the population (Public Health Wales, 2020). As shown in the chart below, after a fall in the number of cases during the summer, cases began to rise during September and at time of writing, most of North Wales is in a local lockdown.

**Chart 1: Testing episodes, confirmed cases, cumulative cases, North Wales**



The number of deaths in North Wales due to COVID-19 in North Wales at 6 October, was between 427 (confirmed cases) and 574 (deaths registered with COVID-19 mentioned on the death certificate).

**Chart 2: Weekly number of deaths registered, all deaths, COVID-19 deaths (any mention) and 5-year average (2015-2019), North Wales**



## Welsh language

The Regional Partnership Board is committed to strengthening Welsh language services and providing an active offer through the Mwy na geiriau/More than just words framework. There are concerns that Welsh language provision may have worsened during the crisis, which has a significant impact on the quality of services delivered, particularly for people living with dementia or receiving mental health services. The Mwy Na Geiriau Forum is continuing to meet and that work will continue to try to ensure that the impact of this is reduced.

The Social Care Wales / Health Education and Improvement Wales Workforce Strategy has also recently been launched and we will wish to work as a region to ensure that the requirements within Mwy na geiriau/More than just words are mainstreamed into future developments.

Guidance around infection control and Personal Protective Equipment (PPE) for health and social care settings is issued jointly by the UK public health agencies on gov.uk in English only (Public Health England, 2020). We will need to reflect on the impact of an emergency situation on bilingual guidance and other initiatives to promote the Welsh language and how to mitigate that in future.

The Welsh Language Commissioner (2020) has raised concerns about the disproportionate effect of the COVID-19 crisis on community activities held through the medium of Welsh and whether people's daily use of the language will reduce if working from home. There is also concern that the number of meetings held bilingually across North Wales has reduced due to the move online. To help address this the Welsh Language Commissioner (2020) has produced a guide to holding bilingual video meetings. There are a number of research projects underway about the impact of COVID-19 on the use of the Welsh language, which we will monitor so that we can including any findings and recommendations in future regional plans.

# Impact on people with care and support needs

## Children and young people with complex needs

### Children with disabilities and/or illness

A rapid assessment from Unicef (2020) states how paediatric health services were limited, with staff moving to adult services and many appointments and planned surgeries cancelled. This could further exacerbate the health of children with complex health needs. Results of the Children in Wales (2020) survey found access to critical care needed to be improved for children with additional health needs. The report from Royal College of Paediatrics and Child Health (2020) also raised concerns about children with long term conditions missing therapies and surgeries, increased waiting times for referrals, delayed assessments and the impact this could have on their health and exacerbation of existing conditions. Special Needs Jungle (2020) reported that speech and language, and physiotherapy sessions were missed for months and worry many children will require intensive support to regain lost skills.

The Unicef (2020) assessment claims the lack of schools and leisure centres for physical activity can be particularly important for children with disabilities, and lack of physical activity can impact the mental wellbeing of children.

Research from Family Fund (2020) found 94% of families felt their child's health and wellbeing had been affected by lockdown and 89% thought their behaviour or emotions had worsened, 65% claimed support like physiotherapy and mental health support they received had declined, and 30% had struggled with the cost of food. Special Needs Jungle (2020) found anxiety levels rose for most children with special needs, however, for some children it was reduced due to less pressure and fewer sensory issues.

In a report from Co-Space (2020) it was stated parents of children with special needs and neurodevelopmental conditions experienced higher levels of stress during the pandemic. Co-Space (2020) and The Disabled Children's Partnership (2020) both found parent carers were stressed and worried about their child's behaviour, wellbeing, home-schooling and catching COVID-19. The survey from All Wales Forum (2020) echoed these findings but also found parent carers were confused by

guidance at the start and many of those who needed to shield were also left confused by the information they were given.

Family Fund (2020) found 74% of parents were concerned about educating their special needs child at home. Special Needs Jungle (2020) found a similar figure of 68%, with 1 in 4 reporting that work was not adjusted to suit their child's needs, meaning they could not complete it.

Co-Space (2020) found parents would like support managing their children's emotional and behavioural problems and they preferred support from professionals in an online format.

The Unicef (2020) assessment details the pressure the pandemic has put on charities, with increased demand and reduced income, means many are at risk of not surviving. Children with complex needs often access charitable services and so this will have an effect upon them.

Universal health care to children was affected by COVID-19 including health visiting and school nursing as many staff were redeployed to frontline nursing training or cover. The restrictions may have had an impact on new parents with restrictions in ante-natal and post-natal monitoring and lack of home visiting in the early weeks and months of birth, which is a critical time to pick up on post-natal depression and issues with bonding and adjustment of family dynamics (partners and siblings).

## **Children who are care experienced**

The British Psychological Society (2020) explain that children who have experienced care may be more vulnerable to the pandemic, having faced insecurity and stressful situations before or they may have had to be alert to danger, which can cause stress responses during lockdown, affecting their behaviour and emotions. Voices from Care Cymru (2020) state how care experienced children are already disadvantaged socially and financially, claiming the pandemic may exacerbate inequalities.

National Youth Advocacy Service (2020) found 50% of children in care and 4 in 5 care leavers felt lonely and anxious during lockdown. Voices from Care Cymru (2020) also found children felt more isolated and anxiety had increased, they claim isolation may impact the mental health of children who have already experienced trauma, and those receiving mental health support may have found this disrupted. The British Psychological Society (2020) claim reduced time with their birth parents may also have an impact on their mental wellbeing. The direct counselling / face to

face contact from Children and Adolescent Mental Health Services (CAMHS) ceased and this will have disrupted the therapeutic journey for all children and their families, whether in care or not.

The Fostering Network (2020) report some foster carers found lockdown challenging, creating behavioural issues but some found the children were more settled. Adoption UK (2020) report among children in care 50% were distressed/anxious and 31% increased violent behaviours. There were positive impacts from lockdown, 50% of teenagers were calmer and 54% had improved relationships with carers/families. In North Wales, weekly calls were made to all placements in residential, Independent Fostering Agency (IFA) and Local Authority foster care provision to monitor welfare which was an increased level of surveillance so that direct support could be offered to maintain placement stability. Laptops were provided to ensure that looked after children could maintain virtual contact with their families and friends as well as ensure they could access on line learning.

In a survey of care experienced children, National Youth Advocacy Service (2020) found 1 in 10 children in care and 1 in 5 care leavers didn't have the technology to stay in touch with family and friends. Voices from Care Cymru (2020) also found care experienced children lacked access to technology to keep in touch. In North Wales, care leavers who needed them were provided with mobile phones to make sure they could maintain contact.

The British Psychological Society (2020) highlight how disruption to care experienced children's education can affect their feeling of belonging, especially if they have had to change schools in the past. The Fostering Network (2020) claim children have lower educational attainment and this disruption to education could further widen the gap. Many carers reported additional learning needs not being met during the pandemic, a significant proportion of care experienced children have these additional needs. Adoption UK (2020) also claim looked after children achieve lower education levels and have higher rates of additional educational needs, they found 85% were not getting extra support from school.

The survey from the National Youth Advocacy Service (2020) found during lockdown, 9 in 10 had contact with their social worker. Discussions with children's services in North Wales found that statutory visits were completed in all cases where there was risk of placement breakdown or stressors had been identified through the weekly calls to monitor placements. The report from National Youth Advocacy

Service (2020) claims many children in care struggled to get in touch with their social workers when needed. This was echoed by Voices from Care Cymru (2020) who found that there was reduced contact from social workers.

In a report from National Youth Advocacy Service (2020) they have seen fewer child protection referrals due to children interacting with fewer agencies, which they believe can make children more vulnerable to violence. In North Wales, there was an initial dip but then the rate of referrals returned to expected levels. An increased level of monitoring visits took place to households where there were children on the child protection register – weekly visits instead of the 10-day timescale. Community Care (2020) found that among social workers, children’s services staff were more dissatisfied, they were more concerned about personal protective equipment availability, and reported an increased workload, with domestic abuse referrals putting a strain on the system.

Welsh Government operational guidance was issued for providers of children’s social care services during the coronavirus pandemic on the continued provision of support to vulnerable, at risk and care experienced children.

### **Children who are in need of care and support**

In a report from Scottish Government (2020) they claim ‘vulnerable children’ such as those in need of care and support were exposed to more risks during lockdown, due to reduced incomes, increased stress on families and being less visible to professionals. Usher et al (2020) also claim the increased financial difficulties, isolation, extra stress and reduced childcare/schooling in lockdown, can exacerbate neglect, domestic violence and abuse in children in need of care and support.

Scottish Government (2020) report Parentline has received four times the usual number of calls and the UK Domestic Abuse Helpline has seen a 150% increase in visits to its website, suggesting those children already at risk could be at increased risk but also potentially more children being in need of care and support. The Innovation Unit (2020) also show increased reports of domestic violence to helplines. The Office for National Statistics (2020) report a rise in domestic violence incidents from police reports during May, June and July, they also report rises in calls to the NSPCC and UNICEF helplines, highlighting the increased risk of abuse faced by children. A report from Women’s Aid (2020) shows how domestic abuse has increased during lockdown, children have both witnessed and experienced more

violence, and access to support and therapies for children who are victims of abuse has been reduced.

Nation Cymru (2020) found data shows 180,000 (1 in 3) children in Wales are living in poverty, and households with children are more likely to have been financially affected by COVID. Nation Cymru (2020) claim children living in poverty are more vulnerable to domestic abuse, and the increase in financial hardship will result in increased risk to children. Sinha, Bennett and Taylor-Robinson (2020) also state that children from poorer families are at greater risk of neglect and domestic violence, and that the pandemic has impacted on finances, with use of food banks increased. All children eligible for free school meals continued to receive this service.

Reports from Welsh Government (2020) show attendance at school for vulnerable children in Wales was below 10% during lockdown and the Innovation Unit (2020) report as few as 5% of children with a social worker attended school during lockdown. The lack of attendance reduces contact with professionals who could identify potential safeguarding concerns for those children at risk of becoming looked after. Donagh (2020) points out school can be the only safe place for some children. In North Wales, a 'Vulnerable Learners Group' met twice weekly at the height of lockdown to make sure that all children known to be vulnerable to risk of abuse and neglect could be discussed and monitoring calls / visits be arranged as appropriate. All high risk children were offered a place at the school day care provision.

Donagh (2020) raises concerns that some social workers have received resistance contacting families, finding it difficult to monitor any escalation of risk of abuse or neglect. Also not being able to support the children alone, due to them being in lockdown with their abuser, means children are missing this support. This did occur in North Wales in a minority of cases with some families refusing contact claiming they were fearful of contracting the virus. This was overcome by use of Personal Protective Equipment (PPE) and meetings outdoors.

Community Care (2020) found the workload of children's social care services had increased during lockdown, this could have impacted on the support children received during this time.

The Local Government Association (2020) report children's social care referrals dropped by one fifth during lockdown, as a result they are anticipating a significant rise in the months following children returning to school. The British Association of Social Workers (2020) also claim social workers could be overwhelmed following

children returning to school, as they predict a rise in referrals due to safeguarding concerns being identified in new and existing children in the need of care and support.

### **Children who are at risk of becoming looked after**

In a report from Scottish Government (2020) they claim 'vulnerable children' such as those at risk of becoming looked after, will be exposed to more risks during lockdown, due to reduced incomes, increased stress on families and being less visible to professionals. Usher et al (2020) also claim the increased financial difficulties, isolation, extra stress and reduced childcare/schooling faced in lockdown, can exacerbate neglect, domestic violence and abuse in children at risk of becoming looked after.

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### **Children with emotional and behavioural needs**

In surveys comparing the start of lockdown to one month later conducted by CoSPACE (2020), parents reported an increase in emotional and behavioural issues in primary school aged children. In secondary school aged children parents reported an increase in restless behaviours but emotional behaviours reduced, however teenagers themselves reported no difference in emotional or behavioural difficulties. They also found parents of children with special educational needs (SEN) reported reduced emotional difficulties but behavioural issues remained the same. This research suggests that children with pre-existing emotional and behavioural needs may require more support, but also more children may present with emotional and behavioural needs who previously didn't need support.

Nonweiler et al (2020) found during lockdown parents of children with neurodevelopmental disorders reported worsened emotional symptoms compared to before COVID-19. Courtenay and Perera (2020) claim those with intellectual difficulties can find it difficult to manage changes to their routine along with reduced access to support and therapies can result in an increase to challenging behaviours. In North Wales, there is concern that waiting lists will have increased, creating more delay for children awaiting assessment and access to services.

A study from Patel (2020) found that children with pre-existing mental health conditions may experience exacerbated symptoms due to lockdown, increasing their emotional and behavioural needs of these young people. Young Minds' (2020) survey also showed children with mental health issues reported relapsing or symptoms deteriorating during lockdown.

Singh et al (2020) claim children with existing conditions that cause emotional and behavioural issues such as mental health conditions and special needs, have been disproportionately impacted by the pandemic. They state how the individual needs of these children will be very different and so it is important that those specific needs are considered, in supporting them and their families moving forward.

The Coronavirus and Me Survey found that the majority (58%) of children and young people said that they felt happy most of the time and a large majority (84%) report feeling safe most of the time. Overall 2% said that they have 'not very often felt safe'. The things that have had the most impact on how they feel are; not being able to spend time with friends, not being able to visit family members and school or college closing (Children's Commissioner for Wales, 2020)

More information on the impact of COVID-19 on those with learning disabilities can be found in the learning disability section of this report. More information about the impact of COVID-19 on mental health in North Wales, particularly for young people, has been pulled together by the BCUHB Local Public Health Team (2020).

## **Children's rights**

There are concerns from the Children's Commissioner that the current rules around self-isolation for 14 days following possible contact with a positive COVID-19 case has significant detrimental impact on children's mental and physical health as well as severely impinging their right to play, particularly in instances where the child does not have access to a garden or outside area.

## How services responded during the crisis

Services have moved to carrying out more work **digitally**, such as using the NEWid Ap to work virtually with children and families and the new virtual engagement tool 'Mind of My Own' for all children to provide their wishes and views in some areas.

**Meetings have moved online and been held virtually** including Fostering and Permanence Panels and Child Protection Conferences. Holding Child Protection Conferences and Looked After Children's Reviews virtually has led to improved attendance and participation from parents and families who find it less threatening.

Some services continued to take place face to face. For example, the Personal Advisor Team continued to support care leavers in Conwy and continued to offer face to face contact where care leavers requested this.

### Home working

Feedback from children's services staff about new **working from home arrangements** has been largely positive. Although as well as social worker's workload increasing many also had to balance home working with their personal child care and home education responsibilities due to their own children being home as a result of school closure. As such the children of social workers should also be acknowledged as having been disadvantaged by the lockdown period.

Positive feedback from one county said that working from home removed the stress of the commute, school run and travel time to meetings, which freed up more time for exercise, healthy eating and time with family. Meetings have been more focussed on the agenda and there has been more engagement from parents and professionals. Online meetings can help give people the confidence to speak up and staff can feel more confident about having difficult conversations with the risk of physical threats removed. Some said that workloads feel more manageable and it's easier to finish on time without being caught by last minute conversations at the end of the day, although this wasn't the case for everyone. Staff also said that they feel more supported by managers who are available by Skype and phone and are checking in with them in a more proactive way than at the office. There are however concerns that as the COVID-19 period has continued and local lockdown has occurred a proportion of social workers, especially newly qualified and those holding the high risk and most complex casework are starting to struggle without the peer support and opportunities for de-briefs on difficult cases, incidents, secondary trauma. This is likely to have an impact on resilience of the workforce longer term.

## **Mental health**

During the lockdown period, the BCUHB Early Intervention Prevention Service (EIPS) has continued to help and support young people and families through services such as run an Arts Project which aims to help with mood, self-esteem and confidence; family consultations have been offered to support families; and CAMHS compiled the COVID-19 resource packs which was sent out to everyone on the waiting list with helpful resources. Links have continued to be made with the school hubs during the school shut down. Professional consultation has remained in place (although this was stopped at the beginning to focus on crisis) to support professionals from other services other than school based. Links have been made with all schools and a new arm of the early intervention service had been set up to support both primary and secondary school clusters through consultation, training and appropriate referrals into CAMHS. There has been increased input into Seasons and Be Smart programmes and friends training is set to be delivered to all schools.

## **Children's services transformation programme**

The programme has adapted to the new situation. **Work-stream one**, early intervention and prevention to improve the emotional health, wellbeing and resilience of children and young people is developing an integrated framework with guiding principles for supporting children and young people aged 0 to 18 years, including guidance and resources. COVID-19 has had a significant impact on development of the framework. The work-stream was paused while senior leadership focused on emergency planning. Recently activity has started to pick up and a survey has been carried out with senior leaders to determine priorities and concluded that the focus should be on difficult family relationships in the 8 to 11 age group.

COVID-19 has brought the emotional and mental health needs of young people into even sharper focus. The programme board has been able to re-direct underspend to accelerate the development and roll out of two programmes: Stay Wise and FRIENDS Resilient, to help children and young people build resilience and improve their wellbeing.

**Work-stream two**, edge of care interventions including multi-disciplinary teams, was affected by COVID-19 in different ways. For example, in some areas, staff were re-deployed during the crisis and rate of progress slowed. In others, delivery continued as planned as it was seen as a priority to ensure children were not admitted to hospital inappropriately or taken into care. The East area team

successfully carried out their MST recruitment and training online and the delivery of the programme was rapidly adapted to online methods so that work with families could start as planned, working with families within 72 hours or less following a referral whose children were at risk of becoming looked after. Progress was also made in the Central area to establish their multi-disciplinary team. Conwy also developed their Behaviour Support Team Pilot and rolled this out across central area. The West area has re-focused its plans for the remainder of this year and is delivering a comprehensive training programme to upskill local authority and health staff to enable them to deliver therapeutic interventions as well as other best practice approaches. Both the East and the West are working with the community and voluntary sector to put in place a community resilience scheme in response to families' immediate needs for support during COVID-19 and in the recovery phase

Another part of work-stream two was the provision of short term residential services which would meet the immediate need for alternative accommodation and enable both a multi-disciplinary assessment and appropriate interventions to be carried out locally in a safe place when staying in the family home is not possible. This work-stream is progressing with property identified East area and progress continuing on the planning permission and site preparation for the new build in Central area.

The transformation programme in the East also identified a high number of calls during lockdown from families whose children were awaiting a neuro developmental assessment or on the pathway and reaching crisis situations. They commissioned Y Teulu Cyfan to support families identified as in crisis or in need of urgent support working closely with Action for Children Disability. The health board also worked with schools to support staff to understand children's behaviours as they returned to school. Flintshire have also commissioned an independent organisation STAND (a community interest company) to provide six online training courses and a parents' forum for neuro developmental families with courses to include Makaton, SLEEP, Teenlife, plus a mindfulness course for parents whose child/ren has a disability.

**Work-stream three**, a pilot in Gwynedd Council to transform children protection practice has been operational for 18 months. The pilot practice framework has been developed collaboratively by practitioners in Gwynedd Council with a view to being rolled out across North Wales. The impact of COVID-19 has been felt directly by this developmental project in several ways. Operating in an area of critical priority practice with families, staff have prioritised emergency response to COVID-19 at the

initial expense of the project's activities. Over time it has been possible to re-establish the planned interventions with staff and individual and group mentoring were delivered virtually. However, from an ethos of forming working relationships with staff, parallel to those better relationships with families; COVID-19 has altered the communication landscape. It has resulted in re-defining the project to make sure it is resilient to be delivered and effective under the new constraints.

Where possible **third sector organisations** have continued to support children and young people through online groups, over the phone counselling sessions and activity packs sent out to families. There have been significant difficulties with moving support online for children and young people including engagement and safeguarding concerns. However, some organisations report good levels of engagement and positive results to online work.

## **Covid chronicles: stories from the frontline**

### **Empowering patients by video**

From physiotherapy point of view, Covid-19 has brought the wider physiotherapy service together. Before Covid-19 sub teams like GP practices, outpatients, Neurology, Paediatrics and other specialists worked very separately. We didn't know who the other teams were, what their roles were, their names or faces. When the majority of staff in outpatient departments were redeployed into acute services, we became one big team. I think that will make services after coronavirus much more joined up. From a training point of view and the knowledge, it's been a positive as staff have gained new skills and now we're going to work on how we can retain some of those new skills.

For the paediatric service, it's been a shocker. The redeployment of paediatric therapists has left children with disabilities across the health board without community services. We have only been operating on urgent priority cases, this was difficult to manage because there was no team left to contact families to see whether they needed urgent therapy.

We did send a letter out to all families on the paediatric physiotherapy caseload to say 'we're still here, contact us'. As although we were re-deployed we were still able to do telephone and video calls and urgent face to face if needed, but hardly anyone contacted us. It appears in the press that the NHS have been too busy with Covid-19. There have been no carers going in to these families, no school and no one to talk to and they're just left at home with a child with really demanding needs.

I went to see a little boy only last week, his mum was really struggling because over lockdown he's been quite poorly and his condition has deteriorated but she

hadn't wanted to bother us. She was struggling with the fact that he didn't appear happy anymore and he wasn't engaging in play and she just didn't know what to do.

He had increases in medication to try and manage his symptoms but that had made him less able to perform physically, for example a side effect for a child might be difficulty in lifting their own head up or managing their swallow. Mum was struggling to manage even his day to day needs, her mental health was really suffering because her little boy was so unhappy all the time.

We spent an hour showing mum easier positions of play so that his head control didn't have to be so good to be able to play with his toys. He then started to engage, smiling and looking at mum and mum read him a book, which she hadn't been able to read to him much because he really struggled to keep in the same position and becomes uncomfortable and we were able to position him well enough that Mum could read him his book and he held a toy that was from the book and he kept on looking at the book and looking at mum's face as she was reading to him and smiling.

Mum emailed me afterwards and said that what a difference it made to see him engaging in play and happy again and it made her feel you know that it was worthwhile persevering and that therapy would start again soon and she just felt a bit more in control. I have to say it made me cry leaving the house because I just felt that I couldn't do enough for them.

There will be an increase in demand for our service when the schools go back. One special school we have over seventy pieces of postural needs equipment that is likely to need adjusting for growth for the child and that's just to make it safe, that's not about checking that that's the best piece of equipment for the child, reviewing their physiotherapy needs, setting new programmes, that's just about getting them safe to start off with.

I think probably the most significant and positive change has been moving to video assessment and treatment because of the empowerment of families definitely, and it's become a much more two-way communication with the families so they're seeing it as more normal to send us short videos of their child or to show us a picture of their child achieving different things where in their home environment, rather than coming in to clinic and telling us and their child not performing very well in a clinic setting. I think seeing the child in their own homes for assessment and therapy via video has been really positive and we will definitely take that forward alongside face to face appointments.

## Unpaid carers

Figures in a report from Carers Week (2020), including data from the Office for National Statistics and a YouGov survey highlight that the COVID-19 pandemic has seen an increase of up to 196,000 additional unpaid carers in Wales by June 2020. 98,000 of these new unpaid carers are also working alongside their caring responsibilities. The Office for National Statistics (2020) data showed a rise in reporting poor mental health among carers, with an even greater increase among female carers. Carers Wales (2020) stated they have seen a rise in people accessing support from the charity with concerns around; their mental health, PPE, testing, food, medicine, feeling invisible or abandoned, and ongoing loss of independence.

In a report from Carers Trust Wales (2020) a number of issues for young carers and young adult carers have been raised. The research found, during the pandemic, young carers and young adult carers mental health has worsened, they are more worried about the future, more stressed, less connected, and their caring hours have increased. Young carers have asked for more support with wellbeing, help to stay connected, breaks, help to balance caring with education and work, and support to stay fit and healthy.

The survey report from Carers Week (2020) highlighted the key challenges for carers in Wales as not being able to get time away, stress and responsibility, financial costs, other relationships, impact on mental and physical health, impact on paid work, and not having anyone to talk to. The report also showed a higher percentage of female than male carers and found that women were more likely to worry about their health and finances. This suggests that women may be disproportionately affected as a result of caring responsibilities exacerbated by the COVID-19 crisis, this could further impact gender equality issues faced by carers. Carers UK (2020) Behind Closed Doors report found the majority of carers in Wales feel; concerned they will burnout, anxious services won't be restored and worried what will happen if they become ill. However, there were concerns that this report did not include sufficient representation from carers in North Wales.

The Wales Carers Alliance (2020) raised issues with Welsh Government during the lockdown regarding confusion over changes to carers' rights in Wales due to the Coronavirus Act, resulting in reduced support plans for some. Other issues that were identified included; being discharged without adequate support, reduced respite

care, confusion over guidelines for self-isolating, as well as the above issues mentioned in the Carers Week (2020) survey.

## **How services responded and supported carers during the crisis**

Despite the pandemic, carers services across North Wales have continued seamlessly, providing a vital and valuable service to unpaid carers through online and distant working. Carers and their families have also continued to receive one to one support should they request, adhering to social distancing guidelines and use of PPE.

Third and voluntary sector services have been supporting carers by: providing shopping and medication collections; carer groups meeting over video calls and individual phone calls; keeping in touch calls including follow-up calls to 'shielding' letters; food and well-being boxes; providing local databases of support available; sharing financial support available through grant applications and emergency grant funds.

Local authorities have been supporting carers by: creating COVID-19 support teams to help people in local communities during the pandemic; sharing key national and local guidance and information about available services; keeping an open dialogue with providers to check how things are going, demand and challenges; working with providers to change services to respond to the new needs of carers and give providers a level of autonomy to make changes as needed; sharing of resources to help with where the demand is; providing increased counselling and emotional support. They have also been carrying out keeping in touch calls; food provision; providing local databases of support available; sharing financial support available through grant applications and emergency grant funds, supporting parent carers with access to education/childcare.

Local authorities have been working closely with County Voluntary Council's to coordinate volunteering and community support, which it is hoped will help to identify and reach informal carers, especially in rural areas.

Promas Caring for People CIC provided free courses for carers around staying well mentally, physically & emotionally, offering hints and tips, allowing carers to identify where they may need more support.

## Main findings

- The number of carers registering with support services has increased during COVID-19 due to more people taking on a caring role as a replacement to support services that may have stopped or been suspended by the family. Lockdown has proven to be very difficult for many carers and has reiterated the importance of future planning.
- Over the past few months the devastating effect of isolation on carers has been evident across the region, and carers have struggled with the lack of visiting at hospitals and care homes.

## Covid chronicles: stories from the frontline

### Coping with caring during COVID-19

“Unpaid carers are a group of people who are under immense pressure, they are often caring for a loved one 24/7. As an unpaid carer during the coronavirus crisis; suddenly your support network around you who might be family or friends disappear, the local authority may be unable to deliver services into your home, the person you care for is unable to go to a respite or day centre three days a week; you are unable to go to the shops because you’re unable to leave your loved one; you are suddenly isolated; alone; your loved one may have died or may be in hospital.

What we’re hearing from our carers is isolation has been crippling. Not being able to be with loved ones as they pass away is leaving regret, it’s leaving guilt and it’s leaving difficulty in the grieving process because they weren’t there at the end.

We started keeping in touch calls with every carer over the age of 70 connected to our organisation. We started with the ones that were most at risk and vulnerable. Eight weeks in we contacted people and they were saying ‘you are the first person that we’ve spoken to. No one else has asked us how we are, normally a social worker or the local authority are involved’. Or ‘my husband’s come out of hospital and no one’s followed up, you are the first person that is contacting us’. This was heart-warming for us to know we were making a difference.

From the beginning of the pandemic we have been delivering ‘Keep Healthy’ food boxes to carers, things like bread, eggs, milk, vegetables – all fresh. We have delivered 2,400 boxes. Typically, that would be delivering to people who perhaps live in a rural area, have no buses and no access to the internet to order shopping online.

We also have a social enterprise arm, our chain of charity shops which closed during the pandemic. We decided to use some of the stock to make 'Keep Busy' boxes tailored to each carer. If the person being cared for liked jigsaws and were happy to do that for a couple of hours, the carer could have a bath or read a book. If you are caring for someone – perhaps you haven't slept and are frustrated, no one is there to help you. Then you get out a game from your Keep Busy box and you can play it with your loved one, you get respite away from your role as being cared for and a carer.

People have actually nurtured relationships. We've delivered draughts to a couple who hadn't played in years. They played every afternoon and the carer said she loved spending time with her husband.

That sounds very simple but unpaid carers have told us this has been a lifeline, we've helped sustain them and kept them alive and well."

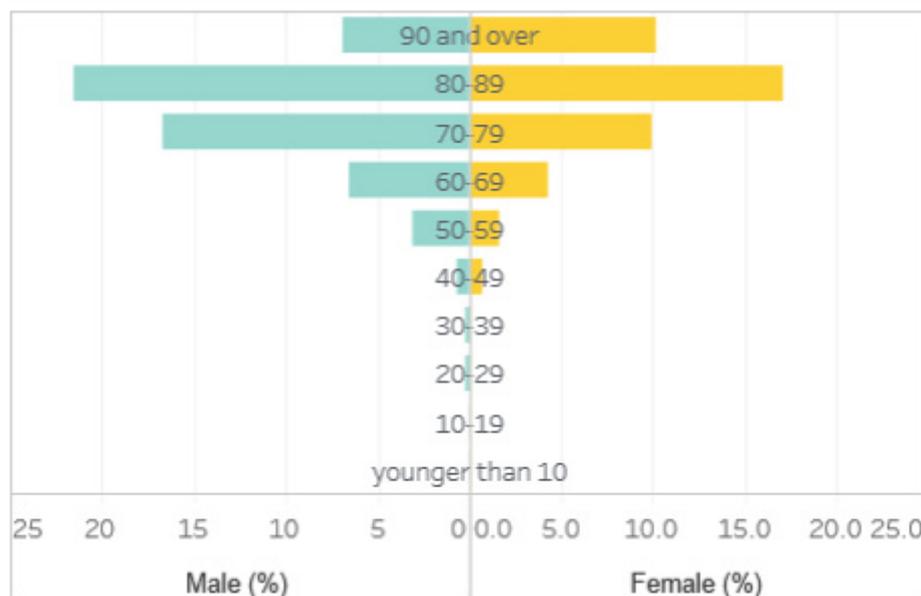
## **Recommendations**

- Reach out to carers who are digitally excluded and ensure equity of services, encourage them to join support groups to talk to other carers and find out, through invited speakers, what other advice and information services are still out there for them to access.
- Consistency across three District General Hospitals around carer presence when the person cared for is having treatment, some services allow the carer to provide support, this inconsistency causes anxiety for both the carer and person cared for.
- Recognise and understand the impact of lockdown on carers and ensure services across all sectors are set up to respond to this to help prevent carer breakdown.
- National/Regional/Local campaign to encourage carers to make a contingency plan where possible and ensure they can cope during the Autumn/Winter.
- We need to work closely with GPs, District Nurses and support services to ask for any information regarding young people who may be young carers. Raising awareness is essential in identifying this group of young people who require support.

## Older people

Chart 3 below shows how much more of an impact of COVID-19 has had on older people compared to younger age groups.

**Chart 3: Age and sex distribution of suspected COVID-19 deaths in lab confirmed cases, BCUHB**



Source: [Public Health Wales](#) [Accessed 26 September 2020]

Kings Fund (2020) state data shows that age increases the risk of dying from COVID-19 due to deterioration of immune systems and being more likely to have chronic conditions. Figures from ICNARC (2020) show age increases the likelihood of dying if admitted to critical care with COVID-19.

The Office for National Statistics found over 50% of the over 60s were worried about their wellbeing, of these 70% were worried about the future, 54% were stressed/anxious and 43% felt bored. They found the over 60s coped by staying in touch with family/friends, gardening, reading and exercise. The data showed they were more likely to help neighbours, less worried about finances, more worried about getting essentials and less optimistic about how long the pandemic would last. Banerjee (2020) also claims older people are more vulnerable to mental health problems during a pandemic and recommends that consideration is made for the mental health of this group, with increased risk of health anxiety, panic, depression and feeling of isolation, particularly those living in institutions.

Hoffman, Webster and Bynum (2020) discuss the implications of isolation on the older population. They claim reduced physical activities, lack of social contact, and cancellation of appointments, can lead to increases in disability, risk of injury, reduced cognitive function and mental health issues. Campbell (2020) also finds social isolation can impact physical and mental health, with reduced physical activity, limited access to resources, loneliness and even grief. Cox (2020) claims the higher risks for older people are further exacerbated by inequalities including; chronic illness, poverty and race, making individuals with long-term conditions, low socio-economic status and Black, Asian and Minority Ethnic (BAME) people even more vulnerable.

The Centre for Ageing Better (2020) claim that although many more of the over 55s have moved online, the digital divide has widened during the pandemic, with more services moving to online only. It is important to ensure that older people aren't digitally excluded moving forward. Boulton et al (2020) in a review of remote interventions for loneliness, highlighted methods that can reduce loneliness including; telephone befriending, video communication, online discussion groups and mixed method approaches. They claim that the most successful involved the building of close relationships, shared experiences or characteristics and some pastoral care. In a rapid review, Noone et al (2020) contradict this, suggesting evidence that video consultations reduced loneliness, symptoms of depression and/or quality of life were inconclusive and more high quality evidence was needed.

Third sector organisations supporting older people across the region have reported two major concerns, the first being digital exclusion and the need to find alternatives for those who don't want or aren't able to move activities online. The second concern has been raised regularly by older people of Do Not Resuscitate (DNR) notices being automatically applied to older people in hospital during the pandemic.

## **Care homes**

Statistics from the Office for National Statistics (2020) show deaths in care homes were up 46% from the same period last year, the data shows as well as COVID-19 deaths, other deaths also increased during this period. They found in Wales age specific deaths in care homes were higher than those not in care homes and COVID-19 deaths in care homes exceeded COVID-19 deaths in any other location. Figures also show men had a higher rate of mortality.

The Older People's Commissioner for Wales (2020) found the supply of personal protective equipment (PPE) to care home was mixed, with some saying there were delays and long waits for more supplies. The use of PPE had been distressing to some who are hard of hearing and care homes had to purchase their own transparent masks. They highlight the issue of lack of availability of tests for care homes, delayed results, lack of information at the start, all of which was felt to have impacted the outcomes in care homes. This reflects local feedback which highlighted the need for clear and consistent PPE guidance with better version control so that it's clear when a document supersedes another or when it is additional to existing guidance. The report also stated how the mental wellbeing of care home residents had been impacted by not having visitors, worries regarding COVID-19 and deaths of other residents.

In reports from House and Fewster (2020) they claim care homes were not prioritised and a series of issues contributed to their high transmission rates these included; the data from care home deaths initially not being recorded, testing not carried out and asymptomatic spread not being considered. The delayed response and lack of clarity to care homes could have contributed to the high number of deaths in care homes. In North Wales, many care staff were working across a number of care homes in a variety of roles which caused challenges for infection control and limited staff employment options and affected their income. There were some concerns about the discharge process at the start of the pandemic, with some providers feeling pressure to accept admissions from hospital to ensure acute bed stability, with no clear process in place relating to testing of patients prior to discharge into a care home. The North Wales Safeguarding Adult's Board also noted abuse of people's rights from the perspective of Deprivation of Liberty Safeguards (DoLS) and decisions being made without referring to the guidance.

## **Innovations/Collaborations**

In a report from the British Geriatrics Society (2020) they highlight some innovations and collaborations to help protect and improve the care of older people during the pandemic, examples include:

- Anticipatory care intervention for those who are high risk
- Multidisciplinary team response to urgent care needs
- Hospital at home collaboration to keep people at home
- Multiagency approach for rapid guidance and support to care homes

- Advanced care planning to identify individual needs
- Children’s ward utilised for elderly patients and found beneficial
- Integrated discharge planning
- Proactive rehabilitation with targeted physiotherapy prior to discharge
- Delivery of telephone and digital appointments

## How services responded during the crisis

“The care providers have been amazing, in particular care homes who have shown great resilience and determination to keep infection rates low”

### Regional approach to supporting care homes

From the outset of the pandemic a range of multiagency planning and reporting arrangements were put in place as part of the overall emergency response. These have been effective in providing high level tactical coordination and operational responses. A health and social care emergency planning group was established as part of the regional command structure alongside a Care Home Cell led by the Health Board with input from Public Health Wales, the Regional Partnership Board, Care Forum Wales and Care Inspectorate Wales. Operational delivery and response arrangements were also put in place at a local authority and area team level to support the sector.

During the pandemic, we worked with partners to change the culture and reduce the burden placed on care homes from multiple contacts. This has developed into a new data collection and early warning system making “one contact a day” calls to care homes. This ensures a minimum data set is collected and shared between statutory partners so that appropriate support is offered in a timely way. This system is still in place although is now happening twice a week. This information informs the North Wales care home escalation and support tool. This dynamic reporting provides early indicators of pressures and issues and allows early intervention and support.

During the pandemic three multiagency Home First Bureau were established to support the timely and appropriate transfer of patients from acute and community hospitals back to their own homes, existing care home or new placement. They are an integral part of the COVID-19 Hospital discharge Service requirements (Wales) and have been essential to the safe implementation of the revised step up and step down care ensuring that negative test results are available for patients before they

are discharged from hospital back to their care settings, or moving between care homes.

### **Keeping in touch**

The Regional Partnership Board provided iPads for care homes and hospitals to support residents/patients to contact friends and families during lockdown and as part of a longer term digital community services transformation project. Support was provided by the Wales Cooperative Centre to help people use the iPads and IT skills of staff have been highlighted as a workforce development issue that will need more support to avoid creating a further digital divide.

Isle of Anglesey County Council developed an emergency contact centre and joint working between Single Points of Access/ and service entry points. Gwynedd Council set up a new team “Tîm Cymorth COVID-19” the five areas covered by the Community Resources Teams and provide information on the council website about local community support services. Conwy also developed a website to list community volunteer groups and businesses. Some care homes have established groups to support each other.

Denbighshire County Council created a Proactive Calling Team, a new temporary service staffed with redeployed employees from across the council. The team made calls to shielding residents and residents aged 70 and over during lockdown and kept in regular contact if the resident wanted this. They offered advice, made sure they had access to food and medication and referred to appropriate services.

Wrexham County Borough Council improved access to the Community Inclusion Grant which enabled care homes to bid for small grants to facilitate alternative and new activity during lockdown. Examples include home cinema experience, home salon, musical entertainment group and sensory garden.

Many voluntary and community groups also provided support including advice, information and buddy schemes. For example, Flintshire council worked with the local County Voluntary Council to support care homes with trained volunteers delivering PPE and supplies.

### **Digital service delivery**

Social Workers used WhatsApp to view the condition of homes by video when physical visits were not possible.

Digital Communities Wales have developed a suite of bite sized modules to support digital inclusion and people's health and well-being in Wales.

### **Flexible service delivery**

Examples include increased opening hours, providing cover over weekends. The way care is delivered changed, for example, commissioning 15-minute care packages in domiciliary care to move people through the system. A council found brokerage is more efficient than ever because of short waiting lists, real time information about people who are moving through reablement so that brokers can better plan their permanent care package. Social workers are not providing individuals with a set time for each domiciliary call, giving providers more flexibility. Providers are undertaking their own reviews of packages and where necessary handing back hours which are not needed and taking on additional packages. Providers have also worked with each individual's resources to support care and support needs, for example, care workers calling morning and evening and family supporting with lunch and tea. Treffynnon care home reopened to provide step down rehabilitation.

The enhanced role of Environmental Health Officers in supporting care homes has been valued and seen as a move away from their traditional regulatory function to a supportive function in helping homes with their infection management plans.

### **Supporting the workforce**

One of the truly inspiring images we have of the pandemic is the heroic work of care staff, which was not necessarily recognised by the media or population at large at the outset of the pandemic. Their personal contribution and impact soon became evident. As a region, we are committed to ensuring that this change of profile is not lost and that we ensure that the needs of individual staff are identified and supported. At least one council has seen lower sickness levels and have introduced occupational health support for their staff and the independent sector as well as trauma support for direct care and front-line social services staff.

### **Services that stopped**

The following services were not delivered during lockdown. Some, such as training, were able to continue online, but others stopped completely.

- Delivering care packages to all those who do not fit into a Priority 1 category.
- Day services.
- Respite / carer breaks.

- Social worker placements in some areas (discussions are taking place regionally about how to support students to complete their degree).
- Face to face training.
- QCF observations.
- Reduced monitoring visits to urgent only.
- Delayed opening of new Extra Care facility.
- Home visits (unless requested by families) although resumed once restrictions changed adhering to social distancing and using PPE.
- On-going podiatry and dental visits. These are key to care home residents' welfare and many homes are keen for these to resume as they have seen a decline in residents' health.

### Provider SWOT analysis

In June 2020 a group of social care and support providers were brought together to discuss and reflect on the shared response to the initial outbreak of COVID-19 in the first half of 2020. This produced the following SWOT analysis as a summary of the key messages (Care Forum Wales et al, 2020).

<p><b>Strengths</b></p> <ul style="list-style-type: none"> <li>• Resilience, flexibility and maintenance of the workforce</li> <li>• Inter-organisational communication and partnership</li> <li>• Independent organisational rapid responses</li> <li>• Membership organisations supporting the workforce</li> <li>• Some responses from external organisations</li> </ul>	<p><b>Weaknesses</b></p> <ul style="list-style-type: none"> <li>• Position of the sector going in to the crisis</li> <li>• Perpetually changing guidance and lack of clarity on implementation</li> <li>• PPE availability early on</li> <li>• Testing policy and implementation</li> <li>• Funding</li> <li>• Collaboration outside the statutory sector sometimes lacking</li> <li>• Retaining the new workforce</li> </ul>
<p><b>Opportunities</b></p> <ul style="list-style-type: none"> <li>• Partnerships: trust and relationships</li> <li>• Commissioning: outcomes and flexibility</li> <li>• Person centred approaches</li> <li>• Workforce</li> </ul>	<p><b>Threats</b></p> <ul style="list-style-type: none"> <li>• Business as usual</li> <li>• Temporary loss of demand for services and perhaps collapse of the care home sector</li> <li>• Loss of recognition for the sector</li> <li>• Complacency</li> <li>• Further pandemics</li> <li>• School return</li> </ul>

## People living with dementia

Figures from the Office for National Statistics (2020) show almost half of COVID-19 deaths up to June 2020 in care homes were residents with dementia during March to June 2020. Further figures from Office for National Statistics (2020) demonstrate people with dementia made up 26% of all deaths involving COVID-19 in March to June 2020. Alzheimer's Society (2020) highlighted statistics that showed non-COVID deaths in April, among those with dementia were also up by 50% than usual. These figures suggest that people with dementia have been disproportionately affected by the pandemic.

Research by Wang et al (2020) suggests delirium from COVID-19 can make it hard to identify COVID in dementia patients, this could impact their care. In a report from Suárez-González et al (2020) it is claimed that dementia patients often have other conditions, further increasing the risk of complications from COVID-19. They also claim those with dementia experience greater functional loss, worse functional recovery, and changes to their routine or environment can further impair cognitive functioning. Research from Mok et al (2020) also found; increased risk of infection, worse outcomes, adverse impact on cognition and these patients were harder to isolate.

The general wellbeing and care of those living with dementia has also been impacted by the pandemic. Alzheimer's Society (2020) argue people with dementia face challenges with infection control and the impact of social isolation. Mok et al (2020) found non-COVID related health care appointments were impacted, lack of social engagement and support may have resulted in a deterioration of their condition, also isolation could affect psychological wellbeing. A rapid review published regarding older people by the Centre for Evidence Based Medicine (2020) highlighted social isolation could impact quality of life, health and wellbeing outcomes, and could reduce mobility. Loneliness has been linked with dementia, so Alzheimer's Research UK (2020) are investing in research to look into the true impact of COVID on mental health, wellbeing, health, and using social care.

The Social Care Institute for Excellence (2020) in 'Dementia in Care Homes', highlight issues those with dementia may have; not understanding the need for isolation, they may find personal protective equipment frightening and they may struggle with communication. The Social Care Institute for Excellence (2020) 'Safeguarding adults with dementia during the COVID-19 pandemic' raise concerns warning people with dementia may be more vulnerable to abuse or neglect during

the pandemic. This may be due to; social isolation, stress on carers, overstretched care staff, increased scams, increased domestic abuse, and new staff/volunteers/support.

Young Dementia UK (2020) share stories from those living with early onset dementia, they highlight issues such as; lack of routine, feeling forgotten, loneliness, isolated, confusion, feeling vulnerable, losing skills, not being entitled to support and loss of confidence. These stories also discussed many positive aspects, with some saying they had learnt new skills, found the virtual support beneficial and one even felt less anxious as going out makes them anxious. The stories highlight how it is important to consider the individual when implementing support for those with dementia.

### **How services responded during the crisis**

Carers Trust North Wales Taith ni clubs for people could no longer meet so met by Zoom. They had to stop most home visits unless families requested when they followed social distancing requirements and used Personal Protective Equipment (PPE) and carried out more telephone reviews.

Alzheimer's Society's Dementia Connect service has 1,437 active service users in North Wales, 646 of these are people with dementia and 791 are carers. Dementia Connect has continued to support anyone affected by dementia during this period and has seen an increase in the number of people requiring local or complex support. Dementia Connect is commissioned by all local authorities in North Wales (with the exception of Denbighshire), mainly funded through Integrated Care Fund (ICF) to provide this support. Denbighshire has also used ICF money to improve support for people living with dementia, by funding grants to community groups through Denbighshire Voluntary Services council and providing two in-house specialist dementia support workers in each of the multi-agency Community Resource teams in the county. More information about the services available to support people affected by dementia in North Wales is available in the service mapping report produced as part of the North Wales Dementia Strategy.

The Community Makers network is a group of people with experience in setting up online communities and groups for people affected by dementia. They are developing a [Community Makers website](#) and building a resource to help groups and individuals who support people affected by dementia to get online and reconnect during the COVID-19 related isolation and beyond. They are exploring the role of

technology in helping groups and members get connected, and creating a knowledge exchange network to share experiences and advice. They are also building a resource of creative ideas to inspire groups with different approaches to digital involvement, including ideas on how to reach people without technology or technical skills.

“Isolation and inability to continue with routines affected people with Dementia. Loss of confidence of going out of the home now evident.” North Wales COVID-19 review, survey participant

## **Covid chronicles: stories from the frontline**

### **Covid Warriors**

“The lockdown of the [residential and nursing] home was so sad because we were having to turn visitors away. Normally they are coming in and out, we know them all and we look after them, they come for dinner with their partners. Then all of a sudden it just stopped and obviously some of them weren't happy about it, they blame you and you felt that you were in the wrong really trying to make them to stop coming in it was a difficult time.

The residents were all isolated in their bedrooms, they had to have their doors shut which was dreadful, it affected their mental health. Our lounge is always very lively usually we have music on, games, people doing crosswords, coming and going, there is a real buzz usually...now there was just me at my desk. It was a bit like a ghost town, you didn't see anybody until you donned PPE and went into a room.

It used to take me two hours just to do a round to give residents a drink and again before I went home. I was stuck doing a thirteen hour shift every day because I needed to be here. One day one of the nurses she came in at ten o'clock and I said 'what are you doing here you're not due in until one o'clock?' she said 'I had to come in it's no good being at home'. We needed to be at home because we were so tired but at the same time we wanted to be here.

We staggered staff testing for Covid-19, there was only a few off at any one time waiting for results, which worked well. I had my test on a Monday, so had to be off during the week. I was constantly in touch with staff whilst I was working from home. We did have to use agency staff over that two-week period but carers were doing extra hours they just all pulled together.

It was such hard work because you're donning and doffing and all that it takes time and it's so warm as well. We were all sweating, we all had roots in our hair, we used to laugh about it. Morale was good and one Saturday the staff called me into the empty lounge and they gave me this lovely bag of goodies of things really

personal for me, bottle of fizz and some chocolate and things to thank me, it made me cry.

You're trying to keep positive for everybody else and as a manager I tried to keep positive for all the staff you know, come on we've got this we're ok you know and inside I'm dying. I think the overwhelming realisation of how much love and protection we have for the residents was there. I used to just dread coming in in the morning because the nights would say oh so and so is coughing and my heart would just sink. We got the virus here in May time, they were the darkest days I've ever had in my career. A lot of the residents we had to test and then we had to ring for the results. On the phone I heard so and so date of birth, so and so positive, and the next one positive, next one positive... it was heart breaking. I was crying on the phone.

Once we had the results of the residents, we had to ring their families to tell them one after the other. A lot of relatives were lovely and they said 'oh gosh it's one of those things, it can't be helped' then you had the odd one 'how the bloody hell have they got that then and who's brought that in!?'.

Residents who passed away with Covid-19 went downhill very quickly. Their families weren't here to say goodbye. Usually we have the family come in and they can pack the room up and you know spend a bit of time give them a cup of tea and all that now we just had to leave the stuff outside for them to pick up, it felt cold. We had feedback from relatives saying 'well she didn't have her favourite earrings on' it was hard to hear that when that was so important for the family. You just felt as if you were failing the families.

It must have been hard for the NHS staff on ICU, they were nursing people they didn't know, it must have been awful and they did a great job. Here, these were people we've nursed for years and we were surrounded by the virus and death. We were grieving for people that we've nursed for so long and their families.

I would have all the authorities ringing, the local health board, public health, social services all ringing for the same information constantly, taking up your time. This was a big issue; I would have somebody ring wanting to do a review at dinner. I'd think why are you ringing at this time? They were all working from home, I was in despair.

Now we have garden and conservatory visits. We've got a conservatory so the residents will come and sit in the conservatory, we'll open up the top window and they just kind of talk like that, a lot of residents are hard of hearing so it is not ideal. You feel very authoritative saying 'no sorry you can't do this, you can't do that', it is difficult."

## Recommendations

In response to the nationally commissioned rapid review of care homes led by Professor John Bolton the Regional Partnership Board has developed a Regional Care Home Action Plan for North Wales. This action plan covers strategic arrangements and operational support for care homes within the region.

The Older People's Commissioner (2020) recommends the following immediate actions:

- Public bodies should take action to ensure that public health messaging is communicated more effectively to older people
- Undertake community-level audits of vulnerable older people who have been digitally excluded during the pandemic and provide user-friendly devices with access to the internet.

The recommendations from the Alzheimer's Society (2020) about mitigating the effects of COVID-19 as we approach winter are below.

1. The NHS and local authorities must set out how they will involve social care providers and care homes in winter pressure planning to ensure that social care is placed on an equal footing with the NHS, and that their situation is understood, accounted for and supported. This must include the provision of regular and timely testing and PPE.
2. National UK governments must guarantee that where care was stopped due to coronavirus precautions (particularly domiciliary care), it will be reinstated when deemed safe, without the need for unnecessary further formal assessment.
3. The UK Government must ensure that the Infection Control Fund remains in place until at least April 2021 and care providers should be able to use that fund flexibly, including for infection control, technology and supporting visits.
4. National UK governments should commit to ensuring that any communications to, or requirements of, people affected by dementia (both in the community and in care homes) are clear, consistent and straightforward to understand. Any guidelines should reflect the daily lived experience and particular needs of people affected by dementia.
5. Recognising the key role that informal carers play in the lives of people living with dementia, national UK governments must take action to support people in this role by:

- a) Allowing for at least one informal carer per care home resident to be designated a key worker, with access to training, COVID-19 testing/vaccinations and PPE.
  - b) Ensuring the delivery of carers' assessments and provision of short breaks for carers.
  - c) Collecting local authority and health authority data on carer assessments and respite care.
6. Where care homes are unable to facilitate visits from loved ones, they must be required to notify national care inspectorates (CQC/CSSIW/RQIA) and seek to put in place suitable alternative arrangements to maintain appropriate contact between loved ones and care home residents who have dementia.
  7. National UK governments needs to set out a clear strategy to enable people affected by dementia to recover from the effects of the pandemic, including rehabilitation to counteract effects on cognitive or physical functioning, support for mental and physical health, and speech and language therapy.
  8. National UK health and social care departments must develop and implement a clear recovery plan to ensure that all elements of memory assessment services can re-open and urgently catch up on waiting lists so the freefall in dementia diagnosis rates does not continue.

## Health, physical disability and sensory impairments

It is unknown what the long-term impact on health of COVID-19 will be for those hospitalised or those with milder forms of the virus, and the impact this has on the need for social care. Around 10% of patients who test positive for SARS-CoV-2 virus remain unwell after 3 weeks of experiencing symptoms and most but not all show improvement over time (Greenhalgh *et al.*, 2020).

Figures from the Office for National Statistics (2020) show COVID mortality rates for disabled people were 1.9 times higher for men and 2.4 times higher for women. Further information from Office for National Statistics (2020) show a greater social impact on disabled people: they were more worried about wellbeing, getting groceries, accessing healthcare and 1 in 10 felt unsafe outside their home. It was also noted their concerns have increased over time, while concerns of other population groups have stabilised.

In a manifesto from Difference North East (2020), it was reported many disabled people were classed as clinically vulnerable and had felt isolated and forgotten, with many not receiving appropriate support. Research from Scope (2020) found 63% of disabled people were concerned they may be refused treatment if they became ill, and they worried about catching COVID from carers due to lack of protective equipment. They also found 28% felt ignored by the government and over 50% were concerned for the future, stressed and anxious.

The United Nations for Human Rights (2020) claim disabled people can be more vulnerable as they often have other health conditions, particularly those in care homes, due to the high death rates. They report that the barriers they can experience in accessing healthcare were exacerbated due to the pandemic. They were more vulnerable to discrimination and violence, this was especially true for disabled people who were; prisoners, homeless or without adequate housing.

Iob, Steptoe and Fancourt (2020) found disabled people were more likely to experience abuse, self-harm and suicidal thoughts. Lund (2020) also raises concerns regarding the increased risk of abuse for disabled people due to increased reliance on care, and expressed concerns they may fail to report abuse due to their reliance on support.

Some benefits for disabled people were reported by Difference North East (2020), including greater use of technology allowing them to connect with others in ways

they hadn't been able to before and home/flexible working benefiting some disabled workers. Although Annaswamy, Verduzco-Gutierrez, Frieden (2020) recognise the benefits, they also highlight that many disabled people can be disadvantaged by the use of technology due to internet and technology costs and mobility or manual dexterity disabilities may create challenges due to difficulties interacting with the technology. They stress it is vital each individual's situation is considered when considering switching from face to face appointments to online.

The World Health Organisation (2020) stated those with physical disabilities may be more at risk of COVID due to; barriers to hygiene, lack of accessible handwashing, being unable to wash hands sufficiently, close physical contact for support, contact with surfaces to support themselves, underlying conditions or reduced access to services they rely on to stay well.

The MS Society (2020) claim some people with MS were classed as 'extremely clinically vulnerable' to COVID-19, some had cancelled appointments, cancelled support, reduced exercise and those living alone felt lonely. In a survey of MS healthcare professionals, Multiple Sclerosis Trust (2020) report that 70% felt services were not meeting needs of people with MS, with rehab being the most cancelled and the service that most wanted to see return.

## **Hearing impairments**

Action on Hearing Loss (2020) report 70% of those hard of hearing are over 70, so at increased risk of COVID-19 so it is vital that information is accessible, both with subtitles and British Sign Language (BSL), and for public health announcements these need to be in place from the start. The British Psychological Society (2020) claim those who rely on sign language struggle under normal conditions, but under lockdown it has been increasingly difficult, this is especially true for Welsh speakers as most interpreters are English speaking. Park (2020) found those with hearing loss struggled as healthcare services, such as COVID-19 testing, being inaccessible.

According to Action on Hearing Loss (2020) the switch to telephone and online appointments can make things harder for those who are hard of hearing, as they often rely on visual cues and lip-reading, they recommend individual consultation to determine communication needs. They also find face to face interactions difficult due to mask wearing, as it is a hidden disability many worried about a negative response to asking someone to remove their mask to communicate with them. The wearing of face masks can be problematic to those with over ear hearing aids, getting them

tangled or damaged when caught in the mask ear loops. Park (2020) also found those who are deaf were negatively impacted by the use of masks. Many of the online technologies are not accessible to those who are hard of hearing, according to Annaswamy, Verduzco-Gutierrez and Frieden (2020).

The National Deaf Children's Society (2020) conducted a survey and found the main issues for deaf children were; loss of their existing support network, lack of access to audiology for repairs or delayed cochlear implant surgery, accessing online home learning materials. If schools insist on face masks and other changes to education that can impact children who are hard of hearing, who are already disadvantaged in education (British Association of Teachers of the Deaf, 2020), this will risk further widening the gap. The accessibility of remote learning is also questioned by the British Association of Teachers of the Deaf.

Action on Hearing Loss (2020) claim some workplace changes can have a disproportionate effect on those who are deaf, like sitting back to back, wearing masks and the erection of physical barriers. Grote and Izagaren (2020) highlight the difficulties they had as hard of hearing healthcare professionals, struggling when trying to discuss important information when people were wearing masks.

People who are deaf face increased isolation due to impaired social interaction (Action on Hearing Loss, 2020), impacted by masks and social distancing. The hard of hearing were less likely to leave their home during lockdown just 54.8% in an average week, compared to 80% of disabled people with a mental health issue, further impacting feelings of isolation.

## **Vision impairments**

Research from the Royal National Institute for the Blind (2020) found social distancing has been near impossible for those with visual impairments, with inaccessible signage and fear of reprisals if they fail to distance, some reported being confronted by others for not socially distancing. This is a concern especially as Henshaws (2020) stated a quarter were high risk and needed to shield and Senjam (2020) found the visually impaired were a group at higher risk of catching COVID.

Royal National Institute for the Blind (2020) research found 74% worried about getting food due to limited deliveries, and 21% rationed food. In a report from Difference North East (2020) they found many disabled people weren't vulnerable enough to get support and struggled to get shopping, many visually impaired people

may have fallen into this category. Many reported losing confidence going out and two thirds felt less independent. Senjam (2020) also reported disruption to support services, and fear of going out had increased feeling isolated, which may impact mental wellbeing.

Royal National Institute for the Blind (2020) found 26% couldn't access information in an accessible format during the pandemic. Senjam (2020) also found those with visual impairments had difficulties accessing information. Survey results from Henshaws (2020), a Greater Manchester based charity, found 41% didn't receive public health information in a format accessible to them. The findings suggest consideration for visual impairments is needed when circulating information in a health pandemic, especially as blind people are at increased risk.

With many appointments moving online, this can be problematic for those with visual impairments, Annaswamy, Verduzco-Gutierrez and Frieden (2020) claim many of the technologies do not meet their accessibility needs.

## **How services responded during the crisis**

### **Remote service delivery**

There was a shift to providing health services remotely. This included GP triage by phone, phone appointments, roll out of video call consultations using Attend Anywhere, eConsult which gives patients a way to contact their GP practice online and Consultant Connect providing access to advice and guidance. Other examples include prehab sessions to help get patients fit for surgery through video technology and equipment and information to take home and the Kidney BEAM project offering an online platform of resources to enhance physical activity.

### **Research and innovation**

COVID-19 research: BCUHB have been able to rapidly and safely set up, open and recruit to COVID-19 studies, supported by committed clinical teams, across all 3 secondary care sites and in primary care. A potential facility in North Wales has been identified for vaccine studies.

A virtual Health Hack was held, in collaboration between BCUHB, the Bevan Commission and M-SPARC on 14 May and 20 May. Winners include a project to develop a short-range communication aid for use while wearing Personal Protective Equipment (PPE); a 'Clear Masks for Communication' project to look at PPE design

for patients with hearing impairments; an idea to create a virtual community based on the Community Care Collaborative physical hub, where people are supported through informal and friendly conversation to access the support they need through a virtual network of partners.

The School of Health Sciences at Bangor University have developed the following in response to Covid-19 in addition to training and education innovations across the university.

1. **Learning from Covid-19:** Resilience survey with health students. The study aims to understand both the external (systems) and internal (personal attributes) influences on students' resilience to the COVID 19 pandemic and subsequent disruptions to their courses.
2. **Critical Care Skills:** Critical Care Skills Questionnaire assessment developed in response to request from BCUHB. This questionnaire is designed to assist with baseline assessment of nurses' knowledge and skills in critical care.
3. **Fast-track course for nurses working in critical care:** [For over 170 BCUHB staff](#)
4. **Research projects** funded by NIHR and NHS England in the context of Covid-19. Currently confirmation of funding is embargoed but there is more to follow in this area.

Third sector organisations across the region have continued to support disabled people throughout lockdown. This support has included telephone and online support one to one and in groups and has ranged from benefit advice, mental health support, activity packs to practical support with food and prescriptions.

## **Rehabilitation needs of people affected by the impact of COVID-19**

The Welsh Government COVID-19 Planning and Response Rehabilitation Task and Finish Group, was established in response to the growing evidence of population need for rehabilitation by people affected both directly and indirectly by the pandemic. The group developed a [national rehabilitation framework](#).

The group has also produced the following resources to support health boards, local authorities and the third sector to plan and develop local services in line with the framework.

- Guidance on services for each of the four identified population groups affected by the pandemic: [Rehabilitation Needs of People Affected by the Impact of Covid-19](#).
- An [Evaluation Framework](#) to understand demand for and evaluate the impact of rehabilitation in the four populations affected by the COVID-19 pandemic.
- A [modelling resource](#) to help identify the potential demand for rehabilitation and the capacity required to meet that demand in order to maximise people's recovery.
- A [legacy document](#) recommending areas of action for national programmes as collectively we recover and re-set the health and care system.

The framework, and accompanying resources reinforce the importance of rehabilitation as a core and integral component of a sustainable health and care system which achieves the vision in A Healthier Wales and build on the innovation and advances made in response to COVID-19 and are designed to inform and support local action to recover and re-set services.

## **Covid chronicles: stories from the frontline**

### **Audiology**

There has been quite a change to dealing with patients with hearing loss during lockdown. We have had to prioritise patients to see them face to face or by video. Our patients have had a tough time, if you've got a hearing problem you may rely on lip reading, people are wearing face coverings of course that's mandated in certain areas like public transport etc. so they have more problems with communication.

If you wear a hearing aid your ears are more likely to block. A lot of GP surgeries have stopped or reduced seeing patients for ear irrigation. Problems associated with this are hearing problems, pain and discomfort. If you've got wax it can make the hearing aid feedback and whistle, which can really drive you potty and everyone around you. GP surgeries would typically treat 5 to 10 patients per week for ear irrigation.

Patients may pay for services privately, but not everyone is in a position to do that so they may self-treat using olive oil. They might purchase equipment which is not safety tested and try to DIY treat themselves which can cause problems.

Lack of access to irrigation at the GP surgery is also going to have an impact on an individual's healthcare now because a larger proportion of GP consultations are over the telephone now and that will be a communication barrier. Video

assessment is preferred for this group but not everyone has the equipment or IT skills.

Now I am back at some GP surgeries I can see patients and treat them, but I can only see a small number myself.

### **Confidence and Covid**

It's very frustrating for me sometimes when I go to the shops and people have facemasks on and I can't understand what people are saying to me. I have to ask them please can you remove put it down slightly and they refuse and they're still talking to me. I haven't got a clue what they are saying and it upsets me. Someone might need to come into the house like the gas service and I panic.

Face shields are a good alternative but you are not as protected. You can get face masks with little windows in them. Deaf people prefer to lip read using the whole facial expression so wearing a mask is still blocking part of your face.

I sometimes suffer with panic attacks, but before Covid-19 I was really happy going out, I'd go to the shops no problem. Now the toilets are closed I get anxious about going to the toilet, I'm scared of catching Covid so crowds are my biggest problem. A few things have happened with communication too so my confidence its lower, it's given me the anxiety. I've been upset while I've been out, my heart's been racing, my palms sweaty I've just thought to myself 'I can't do this'. I mostly I do online shopping now because it's easier and it gets brought to me.

## People with learning disability / autism

A report from Improvement Cymru (2020) found those with learning disabilities had a higher rate of mortality than the general population in Wales. Statistics from the Care Quality Commission (2020) also showed an elevated mortality rate for those with a learning disability, compared to the same period last year. Mencap (2020) have raised concerns about the disproportionate impact on mortality of those with learning disabilities, higher than that found in care homes. The Welsh Parliament (2020) report 'Into Sharp Relief', stated how COVID had widened inequalities in terms of mortality, income, risks of COVID and they point out how those with special education needs may have fallen further behind. Courtenay and Perera (2020) claim those with a learning disability are at increased risk of infection and experiencing more severe symptoms.

The North Wales Learning Disability Transformation Programme raised concerns about increasing health inequalities including the temporary stopping of Annual Health Checks during COVID-19 and pause on planned work to increase uptake of health checks. There are also concerns about the availability and accessibility of nasal spray flu vaccines to people with learning disabilities who become seriously distressed with needles and whether this will be an option for a potential COVID-19 vaccination. If a nasal spray is not an option for a COVID-19 vaccine, then support will need to be available to people with learning disabilities who are needle phobic as part of the plan to roll out the vaccine and maximise uptake.

The Learning Disability Consortium Wales (2020) found some people with learning disabilities didn't receive shielding letters when they should have and others were confused by the letters, they had issues accessing food, supplies and healthcare appointments (some found telephone appointments problematic). Those with learning disabilities who are employed have had to learn new ways of working and using transport safely.

The Third Sector Additional Needs Alliance (2020) claim families of children with complex needs have found it challenging, as school can be a form of respite. They found the children and young people they support, felt isolated and experienced accessibility issues with learning. Courtenay and Perera (2020) claim withdrawal of support; school, day centres and respite, will affect the finances and mental wellbeing of families/carers. They also point out that the change of routine and physical restrictions can cause anxiety, paranoia and behavioural problems, in those

with learning disabilities. The Learning Disability Consortium Wales (2020) also reported those with learning disabilities and their families were more anxious about the virus, safety of their support, new rules and losing support.

Learning Disability Wales (2020) discussed the use of technology, claiming those with learning disabilities can be excluded due to; costs, lack of skills, needing help or inaccessible technology. During lockdown many support groups moved online which has benefited some, attracting those who would not attend physical groups.

Learning Disability Consortium Wales (2020) highlight positives of the pandemic for those with learning disabilities including; learning new things, excellent community support and the Welsh Government being largely responsive to their needs.

In the early days of the pandemic, organisations such as Learning Disability Wales, Mencap and All Wales People First led successful campaigns to draw attention to ethical decisions being made around people with learning disabilities, showing the continued risk that people with learning disabilities could be treated differently as a result of having that label.

## **What people told us**

These national findings are consistent with local reports. Day service settings shut down and social care and health community staff worked from home. In-house services appeared to adapt less quickly to lock down though contracted out services such as HFT, Tyddyn Mon, Co-options were able to adapt more quickly and offer online activities to those known to their services. Some quotes from families in North Wales are listed below;

“We felt we weren’t in the loop initially and that we were abandoned.”

“Did services talk to families because we should have put our heads together?”

“Our world suddenly became very small”

Citizens report losing their employment or having been away from volunteering opportunities having had a detrimental impact on their wellbeing.

“If it had not been for Conwy Connect, Transformation team, All Wales People First and the participation groups what would we have had? We needed to be connected. We need those activities to continue”.

## **Coming out of lockdown/shielding**

- Families and providers are anxious about individuals leaving isolation particularly given their physical health vulnerabilities.
- Support has to be bespoke and person centred and practitioners are having to rapidly review and redesign each person's day, requiring a great deal of input to review complex behaviour support plans and so on.
- There are concerns from people with learning disabilities and their families around approaches being taken to shielding and the restricted use of "bubbles" within shared supported living. While well intended, the result of some of these practices could have significant impacts on the rights, liberty and relationships of people with learning disabilities, do not always adhere to national guidance and therefore have a disproportionately draconian effect on people with learning disabilities living in these settings.

## **Workforce and availability of support**

- Support workers report feeling exhausted. The workforce was depleted by people being off sick, self-isolating or furloughed. Again this is supported both by Paradigm and local experiences. Social care staff feel underpaid and undervalued particularly when compared with health colleagues.
- Gwynedd reported having the buildings available to provide respite, breaks and day services for people. Their issue was the lack of availability of staff. The care homes and 24 hour supported living services had to be prioritised, meaning staff hours were taken away from bespoke domiciliary support options that might have alleviated the stress on families.

## **Digital inclusion**

- One local supported living provider reported challenges in supporting people with learning disabilities to access Zoom and other technologies as staff did not always have time to sit with individuals.
- A lack of skill and knowledge amongst those supporting people with learning disabilities, a lack of or restricted internet access and lack of access to equipment are the main issues barriers to digital inclusion.
- Statutory day services have stated they would have liked to have offered more virtual activities and meet ups, the digital infrastructure and skills were not in place to set this up.

- A number of citizens and advocates reported reluctance amongst providers and carers to allow people with learning disabilities to access the internet citing risk and confidentiality factors.

### **Guidance and availability of accessible information**

- Agencies referenced the pressures of receiving large amounts of guidance, usually by email from several authorities at a time of pressure on their services. This was exacerbated for national providers who had to familiarise themselves with English and Welsh guidance.
- While easy read guidance and videos have been helpful, the production of materials has not always been timely and circulation of materials has been patchy.

### **Autism**

The National Autistic Society (2020) in their report 'Left Stranded', claim the pandemic has disproportionately affected those with autism and their families. The research found compared to the general population, those with autism were 7 times lonelier and 6 times more likely to have low life satisfaction, and 9 in 10 were concerned about their mental wellbeing. Ghent University (2020) also found those with autism had higher levels of anxiety and depressive symptoms.

Eshraghi et al (2020) claim disruption to routine can be especially distressing for those with autism. They point out some may struggle with social distancing, mask wearing, and may not understand the need to follow these rules. Ghent University (2020) also found adults with autism found following the new rules difficult making them anxious especially when shopping, and struggled with changes in routine.

The report from the National Autistic Society (2020) found those who require constant support were significantly more impacted by lockdown. It was also found adults with autism need for support increased, with many who didn't require support now needing it, (Ghent University, 2020). The National Autistic Society (2020) found the increased need for support had impacted many families, with 1 in 5 families reducing their working hours due to increased caring responsibilities.

The National Autistic Society (2020) reported how the education of those with autism had been impacted, with 7 in 10 parents struggling with the school work and half of parents felt their child's educational progress had been impacted.

## **How services responded during the crisis**

### **Technology**

The use of technology has increased, including use of digital platforms such as Zoom/Facebook/What's App video. Engagement with social media, short videos, Facebook live and so on has increased, enabling more direct contact and correspondence with the community. Some areas made IT equipment available to some citizens in residential care and supported living through ICF funding and others and where this was provided, it proved beneficial.

Online activities such as quizzes, bingo, discos (mostly provided by the third sector organisations, person centred practice and advocacy groups), have worked well for people with learning disabilities and their carers. They provided routine activities for citizens, respite for carers, and invaluable contact for all. Citizens, families and providers reported that routines, including routine virtual activities, were crucial to minimising the negative impact on wellbeing and feelings of isolation.

The North Wales Integrated Autism Service has trialled and evaluated assessments by video conferencing from 27 May 2020. The outcome of the evaluation was to continue to offer video consultation even after COVID-19 restrictions are lifted. The size of the North Wales region means that video consultations can be rolled out to all clients which will help reduce travel costs and overcome the challenges of finding suitable venues for face to face interviews.

### **Collaboration**

Peer support and sharing of information, within the third sector worked well. These organisations proved to be more agile and adapted to lockdown quicker than some.

Easy read guidance has been helpful for families and individuals. Advice and support from organisations such as All Wales People First, Learning Disability Wales, North Wales Advocacy Association, Mencap Mon, STAND, Conwy Connect and many others has been circulated via social media and has been invaluable in informing families of rights and regulations, particularly when these issues were complex.

### **Direct Payments**

Those with Direct Payments in place have been able to continue a level of support for individuals with Learning disabilities, albeit the use of those payments has been impacted by the availability of staff, fears around the vulnerability of individuals and

families thorough having contact with support workers and so on. There are also unresolved issues around payments of retainers that need to be considered in local authority teams.

### **Provider forums**

Provider forums in Denbighshire and Anglesey were cited as being helpful in the support of providers.

### **Covid chronicles: stories from the frontline**

“When I was a child I was diagnosed with Asperger’s syndrome, now called Autism Spectrum Disorder. I have Dyspraxia and have trouble with my walking and balance because I have mild Cerebral Palsy. Two years ago I had a lot of trouble... At that point I got a support worker who helped me with my problems. Before Covid-19 I was up and down recovering, but coping, I was still doing things with the Community Mental Health team.

I had a couple of calls from the Community Mental Health team at start of lockdown and then they started the Zoom in May or June but they didn’t really carry on with that. It’s once a week but quite a few times they cancelled it just like doing a quiz just for an hour once. I haven’t had regular phone calls every week or anything to check in to see how I am and how I’m doing if anything I’ve been with everything.

I’m a tough cookie but I would like more support for middle aged people. I’m 31 years old, there seems to be an emphasis on the elderly on the news. Services for the elderly people like older adults saying they’re isolated they’re alone but there’s a lot of middle aged people who are.

The changing rules have been confusing and stressful, people with high functioning Autism find it hard to process changes especially when they’re brought in fast paced and there has been conflicting information for England and Wales and misinformation on social media. Was I going to be allowed out more than once a day? What are the police going to ask me? Will I get fined? It’s been mind boggling. It would be good if there was information specifically for people with Autism to read.

I’m still spending a lot of time on my own, I’m trying not to go out as much because the rules have changed with the face masks, I will wear one even though I don’t have to wear one because technically I’m exempt because of my autism but I feel like I have to wear one because I’ve heard people are getting hassle for not wearing one. For people with autism they can’t bear the feeling of the mask on their skin.”

## Recommendations

### Recommendations from All Wales Forum of Parents and Carers of People with Learning Disabilities (2020)

1. Reinstating meaningful engagement opportunities for carers and carer services across Wales, helping shape the road map for recovery going forward; specifically, at strategic levels in co-designing solutions that will really work, and not just as responders to consultations.
2. Clear shared plans and reassurance that carer support services and the community services they rely on, are not at risk of being 'non-essential' going forward; specifically seeking to restart the assessment process as soon as is practical, with digital communication methods used in meantime, and also the re-starting of regional partnership working with confirmation of funding for local community support.
3. Respite in all its forms including short breaks, creative direct payments and day services, should be seen as a priority when considering next steps of support; specifically enabling flexible approaches to the use of Direct Payments.
4. Providing clear guidance to families with SEN children for returning to school as soon as is practicable; specifically providing guidance to families around the support that schools will receive to manage risk for this particularly vulnerable group of children, and also guidance to support young carers, including siblings, if someone they care for is shielding in the family.

### Recommendations from the North Wales Learning Disability Transformation Programme

5. Staff will need to skill up in relation to knowledge of technological applications. They will also need to develop confidence and skills in their use and set aside their own risk aversion and other prejudices against use of technology if that approach is to be fully taken advantage of. The value of internet access and technology needs to be appreciated and individual and service led investment made in this area.
6. Any future promotion or supply of technology such as phones and iPads needs to include access to technological support for individuals, families and support workers as initial problems with access very quickly put these individuals off using that technology rendering it useless from the very start.
7. Continued access to equipment, internet access and so on will be critical to responses to future outbreaks and will enable quicker adaptation to future

lockdown situations. In addition, a larger stock holding of equipment will be required, particularly that sourced from overseas.

8. Services will need to consider and evaluate how citizen need will be met in the event of further lockdowns and a need for citizens to self-isolate. Some quotes from families are listed below;

“Finding a way to still see the staff from the day services (would have been good). It would have been good if they could have done zooms, maybe of themselves doing the usual work and having a chat or thinking of something he could have done from home with them. Even just a chat with a cup of tea.”

“He needed to see friends. Needed some sort of organized online meetings. We couldn’t ring other families up because we didn’t have their numbers.”

“Craft packages or activity packages to match with a zoom session by the usual staff from the day services. If it’s cooking, send the recipe a week beforehand”.

## People with mental health needs

In a press release from the Royal College of Psychiatrists in May (2020), psychiatrists have reported a 43% increase in emergency appointments and a 45% reduction in routine appointments, they warn of a surge in mental health cases could be ahead. The report from NHS Confederation (2020) reflects this prediction, highlighting increased referral rates, higher than pre-lockdown. They are expecting further rises with; those with existing mental health issues, those relapsing and new patients. Statistics from the Office for National Statistics (2020) show depressive symptoms doubled during lockdown with 1 in 5 adults experiencing some form of depression. Mind (2020) reported 1 in 5 people in Wales were unable to access mental health support at the start of lockdown, they claim this can lead to people reaching crisis point and needing emergency care. Mind, also report increased access to their online services.

Reports from the Mental Health Foundation (2020) and the Centre for Mental Health (2020) highlight the disproportionate impact on the mental health of people from Black, Asian and Ethnic Minority (BAME) groups and those facing financial insecurity, lower income households. The Centre for Mental Health (2020) also highlight other groups where lockdown has had a disproportionate impact on their mental health, including; those with existing mental health problems, those with long-term health conditions, older people and those subject to trauma/violence in lockdown. Usher, Bhullar and Jackson (2020) argue it is important to recognise that isolation can have a more severe impact on children, older adults, minority groups, lower socio-economic groups, women and those with pre-existing mental health conditions. Iab, Steptoe and Fancourt (2020) found these groups were more likely to self-harm and have suicidal thoughts, as well as disabled people and people with COVID. These inequalities were echoed in a report by Mind (2020) 'The Mental Health Emergency'.

In a survey of those with pre-existing mental health conditions, from Rethink Mental Illness (2020) 79% reported their mental health had worsened due to the pandemic. Over 50% exercised less and ate less healthily, this could result in worsened physical health, which could have implications on those with severe mental illness whose life expectancy is already reduced. Those with mental health issues are more likely to gain weight due to medications and lifestyle, this may put them at higher risk of severe symptoms of COVID.

## **Age groups**

A study from Mental Health Wales (2020) showed one third of children experienced mental health issues during lockdown. Alfven (2020) also reported an increase in anxiety and depression amongst children and raised concerns about how; missing education, poverty, malnutrition and inequalities may exacerbate these problems.

It has been found (Vernooij-Dassen, Verhey and Lapid, 2020) that social distancing during the pandemic has had a negative impact on the mental health of older people, including; anxiety, stress and depression. Webb (2020) states as well as increasing anxiety, stress and depression, the pandemic can reduce their resilience and feeling of self-worth.

The Coronavirus and Me Survey found that the majority (58%) of children and young people said that they felt happy most of the time and a large majority (84%) report feeling safe most of the time. Overall 2% said that they have 'not very often felt safe'. The things that have had the most impact on how they feel are; not being able to spend time with friends, not being able to visit family members and school or college closing (Children's Commissioner for Wales, 2020). The early findings from the HAPPEN at Home Survey (2020) found that children's worry levels were the same as before lockdown and 91% said they could stay in touch with friends.

## **Pregnancy and Postnatal**

Women are at higher risk of mental health problems during pregnancy and postnatal, Durankus and Aksu (2020), and Babies in Lockdown (2020) found depression and anxiety were even higher in this group of women during the pandemic. Babies in Lockdown (2020) found the increase in anxiety and depression was higher for BAME mothers and lower income families. Both reports state how mental health can impact the pregnancy and the baby, so it is an important issue to avoid long-term complications, and to address the greater impact this has had on disadvantaged groups.

## **Alcohol use**

Research from Alcohol Change UK (2020) found among current or former drinkers, 28% had been drinking larger quantities and 21% had been drinking more frequently. They also found of those drinking more, 40% said this was due to stress or anxiety, and 1 in 6 felt concerned about their level of drinking. Research from Wardell et al (2020) suggests solitary drinking and drinking as a coping mechanism, both of which

increased in lockdown, are associated with drinking problems. The research indicates that issues with alcoholism may be more of a concern due to the pandemic.

More information about the key messages for social workers about alcohol and COVID-19 are available on the [Social Care Wales website](#).

## **Eating disorders**

Castellini et al (2020) found lockdown had a significant impact on those with eating disorders, causing post-traumatic symptoms and impaired recovery, this was particularly prevalent in those who suffered early trauma or attachment issues. In a study by Baenas et al (2020) it was found that symptoms of eating disorders were exacerbated during lockdown.

## **Obsessive Compulsive Disorder (OCD)**

A case is discussed by French and Lyne (2020), in which they claim those with OCD are potentially at increased risk of relapse during a health pandemic, such as COVID, and express the importance of supporting this vulnerable group.

## **COVID-19 Survivors**

In a review of the literature, Kaseda and Lavene (2020) claim there is a high likelihood of psychiatric symptoms and disorders in COVID-19 survivors, including post-traumatic stress disorder (PTSD). Lyons et al (2020) also report high incidences of post-viral depression following previous similar viruses and warn this could be the case with those recovering from COVID-19. Rogers et al (2020) warns clinical staff should be aware of the possibility of PTSD, depression and anxiety, following recovery from COVID-19.

## **How services responded during the crisis**

- Conwy Mind set up a Virtual Hub and counselling services through the lock-down, using emergency funding from the Steve Morgan Foundation.
- The Isle of Anglesey invested an additional £50,000 in the Parabl service to provide additional capacity for bereavement and mental health services. This included counselling sessions, CCBT serenity sessions, virtual 'coping with life' and 'mindfulness' sessions.
- Anglesey links with Police Community Support Officers (PCSO) who have local knowledge and are aware of residence who have may mental health needs,

including dementia. This has resulted in older residents who are self-isolating feeling reassured by (socially-distanced) checks on their well-being.

- ICAN support provided over the phone following a referral, after volunteers were taken out of GP surgeries and unscheduled care due to COVID-19. Have now had 700 referrals across North Wales and each area has 12 to 15 volunteers providing support. A lot of support is available to volunteers. Tuesday afternoons have been set aside for training. Support is available for any escalation and after every call if needed, but a minimum of one supervision every 2 weeks. There is also a once a month Zoom supervision for volunteers to speak to each other. People's ratings from before and after the support shows that it does help to improve their mood.
- Remote delivery of Active Monitoring (CBT based guided self-help) which has included adapting materials for online delivery and has been successful so far.
- Numerous third sector mental health organisations across the region including (but not limited to) Kim inspire, Advance Brighter Futures, Breathe, DPJ Foundation, Cais and more have continued to offer one to one and group mental health support throughout the pandemic.
- Many third sector organisations and community groups across the region have established befriending services to combat loneliness.

## **Recommendations**

Reflecting on the results of their survey, in a statement on 30 June, Mind (2020) state that the pandemic has been a mental health crisis and mental health needs to be central in recovery plans. They claim the full impact on mental health is yet to come with increased; unemployment, financial and housing difficulties. A briefing from Centre for Mental Health (2020) recommend support with financial instability which can cause mental health problems, proactive mental health support for COVID-19 sufferers and health and social care staff, and the use of trauma focused approaches to support schools, health and social care, and businesses.

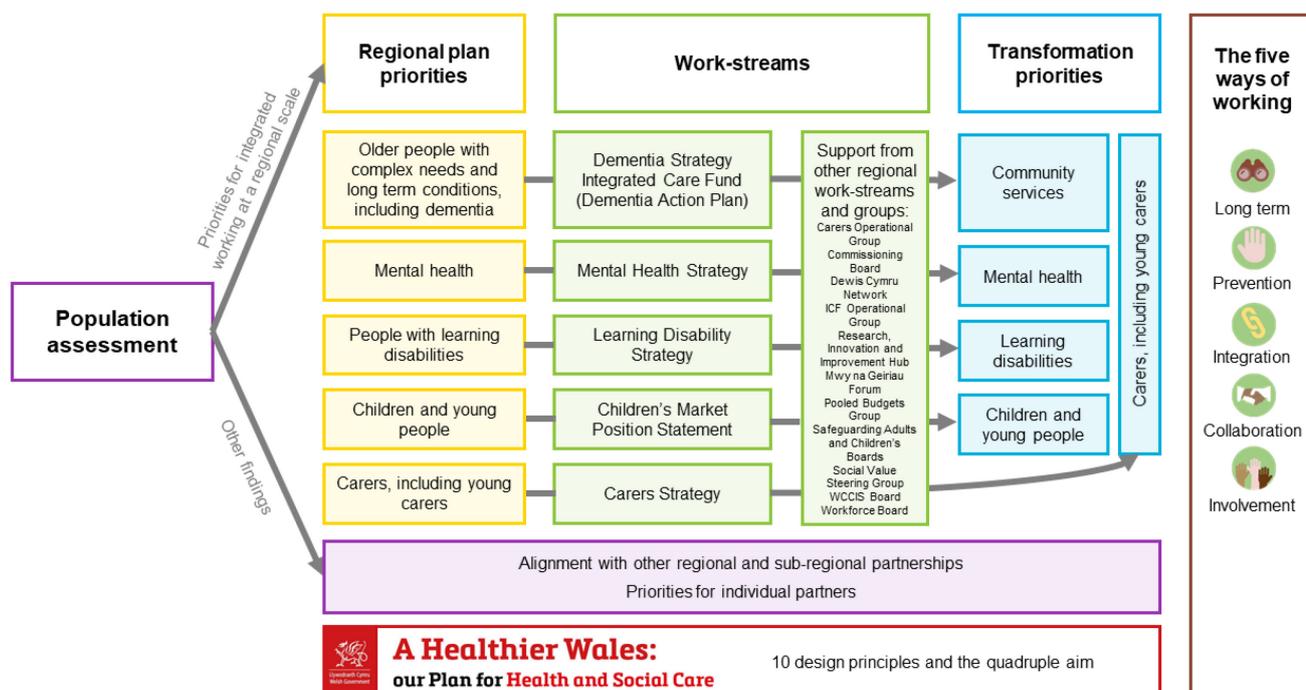
# Conclusions and recommendations

The Regional Partnership Board developed priorities for integrated working based on the original population assessment, which were:

- Older people with complex needs and long term conditions, including dementia
- People with learning disabilities
- Carers, including young carers
- Children and young people
- Mental health

The diagram below shows how these priorities link to the transformation priorities and other regional work-streams.

**North Wales Regional Partnership Board: overview of priorities**



This rapid review of the population needs assessment supports the need for the Regional Partnership Board to continue to focus on these priorities. There are also some consistent principles which the rapid review identified for this work.

1. **Promote digital inclusion.** This includes making sure people who use and provide services have access to technology and connectivity along with the skills to use it.

2. **Inclusive approaches to service redesign.** While there have been many benefits to remote working and increased use of technology during the pandemic, these approaches do not work for everyone nor do they work in all circumstances. As services adopt new ways of working, they need to be carefully evaluated to identify and mitigate any potential harm. For example, by taking a blended approach to service delivery to maximise the benefits of virtual and face to face approaches.
3. **Take a rights-based approach** to future lockdowns and reopening of services to mitigate harm caused by policies designed to control the spread of the virus. This must include involving people who use services in co-producing policy and response and having voice and control in their own lives.

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