



**All Wales Forum of Parents & Carers of People
with Learning Disabilities (AWF)
Fforwm Cymru Gyfan i Rieni a Gofalwyr Pobl
ag Anableddau Dysgu (FfCG)**

Living with the COVID-19 pandemic:

Learning Disability Family Carers in Wales – ‘*what matters’* to us?

A short report to share the experiences of life in lockdown for parents and carers of people with learning disabilities and how we can ensure they get the right support moving into the “new normal”

From the All Wales Forum of Parents and Carers of People with Learning Disabilities





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Overview

The All Wales Forum of Parents and Carers of People with Learning Disabilities is unique among Learning Disabilities bodies in Wales in that it is the only organisation that represents nationally, collectively and solely the views of Parents and Carers of people with learning disabilities and autism, and is governed by family carers directly. We are an umbrella network for locally and regionally based organisations and support groups made up of parents and carers, that currently reach out to over 4000 families. Our wider alliance partners share a commitment in working to improve the rights and recognition of parents and carers and families supporting loved ones living with learning disability. We value working co-productively to make meaningful differences to the lives of families across Wales.

The All Wales Forum has conducted a short survey to build a bigger picture of how well families who care for somebody with a learning disability are coping with life in lockdown. We have also received numerous requests for information from families around their current support packages and how lockdown has affected these.

This is an extremely stressful time for Learning Disability and Autism families, and for most, a huge disruption to their very structured lives. Most of the families connected to our networks will rely on schools, day services, and other forms of community structure and support to enable them to function as a family.

Some carers within our network have noted they are currently ‘coping well’ with life in lockdown. “Coping well” for learning disability families is not the same as “coping well” for the general population. The lives of these families are often intense and require round the clock care and support. The pausing of many support mechanisms has understandably placed extra pressure back onto the shoulders of this caring group, and it will not be a sustainable solution.

It is important to remember carers are a hidden group who invariably do the best with what they have, and by their very nature, tend to continue to ‘manage’ in spite of circumstances. However, this does not make it morally or ethically correct to leave them to ‘manage’ with minimal engagement and support for any longer than in essential.

Each year Carers save the Welsh Government the entire annual cost of the National Health Service by caring for loved ones. Families in our networks will need extra support, and meaningful co-produced conversations and planning, to feel confident to transition back towards ‘normal’ life as we move into the next few months post lockdown.



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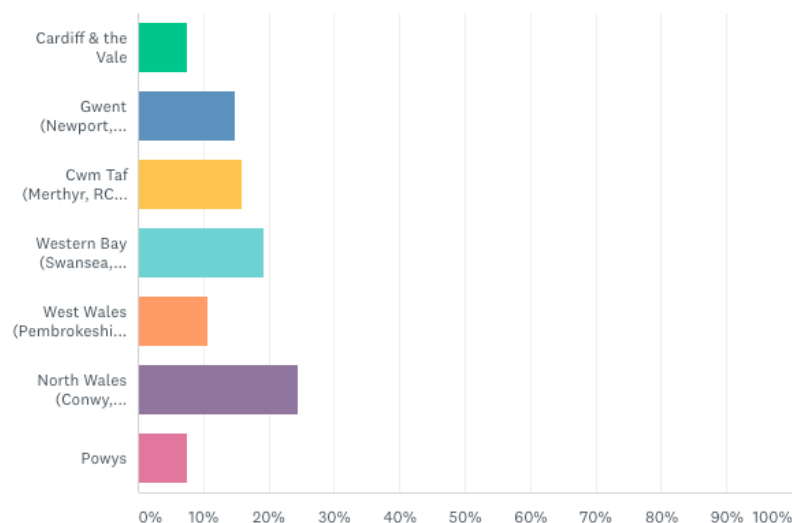
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We wanted to find out what struggles families have faced so far in managing through the COVID pandemic, how they have managed to access support, if at all, and what help they will need as lockdown begins to be eased. This report will outline the main concerns facing families in Wales at the moment and what help they want to be able to access after lockdown has ended and we transition into a new society. The evidence for this report has been drawn down from our quick survey, wider discussions with LD family network groups and individual carer concerns and queries that we have received at the AWF main office.

The Survey demographic spread;

Which region do you live in?

Answered: 94 Skipped: 1



Advice & Information

Many carers mentioned the lack of clear and precise information for LD families at the start, and the initial guidance had been confusing leaving families anxious about what things mean for them. Families are grateful that Wales Learning Disability Consortium Partners have been instrumental in working together with Welsh Government and Improvement Cymru policy leads to ensure that relevant guidance is translated into easy read and information shared by network partners out to families. However, much of this has taken time, and therefore many families have felt in limbo while they were waiting.



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Many families are shielding as a result of extreme vulnerability, either for them as carers, or for the person they are supporting. The guidance around shielding has been very confusing for many and they feel that there has been a lack of specific instructions specific to people with Learning Disability. Especially to be able to clarify what to do if you did not receive a shielding letter, or if your GP has described you as 'vulnerable'. Carers who have their older children living at home have especially found it difficult to be recognised as needing help with shopping and accessing food delivery slots for example.

Services

Some of the services people once relied on such as day centres, community activities and schools have made resources available for families to access online which has been helpful. However, many families are not computer literate and though technology has been wonderful during lockdown in keeping people connected, there are still some who remain isolated. Equally, some families have reported issues with relying on the internet, when they live in areas where broadband access remains poor. There are also some families where digital poverty is a real issue –with many resources requiring the ability for people to have adaptive technology.

While all families who have been in contact and responded to the survey understand the pausing of community resource, there is growing concern about how long the pause will go on for, the lack of being able to contact their own social worker and also if crisis situations will be generated through the long-term lack of practical support. This is a balancing act where families would like to have greater engagement with local decision makers to be able to feed in their thoughts on how to overcome some of the issues together.

Staying connected

Many carers are managing to stay in touch with their carer peers/networks through a variety of ways; phone, email, Zoom/Skype, and managing to access information and advice through peer support, which has eased some concerns. Being able to speak to somebody in a similar position to them is helpful. However, many have also cited that they miss the ability to catch up face to face, and they would welcome some further guidance around the recent announcement of two households meeting up. Specifically, in an easy read format that they can share and talk through with their loved ones. Isolation is an endemic issue for carers, pre-covid, so it is crucial that carers remain as a priority group with regards to reducing loneliness and isolation going forward.



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Mental health and Well-being

Families are clearly concerned with the mental health of both themselves and those they care for. COVID-19 has increase anxiety generally across the wider population, but for family carers there are heightened reasons for concern around mental health and well-being.

One carer commented, “an occasional phone call to ask if we’re ok would be helpful.”

For example, a perennial anxiety heard from families who have been in contact is what happens if a carer falls ill and cannot care for their son/daughter child. The lack of engagement for many with their social worker to be able to put in place a ‘plan’ should an emergency situation occur has only served to increase concerns.

The daily briefings from the government about the mortality rate from coronavirus reinforces personal anxiety. Some positive information about how science is working together to help find answers would be useful in bringing some hope that there will be ‘life after lockdown’.

There is little accessible guidance on death and grieving available to people with a learning disability, causing additional stress to parents having to explain, and reassure when they themselves are fearful and anxious. Equally, many families remain fearful about taking their first steps outside their homes for fear of making wrong decisions. Again, this is where more detailed conversations with key stakeholders, such as the All Wales Forum and our wider LD consortium and Carer partners, is essential in shaping information and guidance.

Respite/short breaks

Respite, or taking a break, has always been an integral service for both carers and the person they care for. While many carers understand why respite services are postponed within the current pandemic, families are facing considerable additional stress and heightened emotion by the increase in their caring role with seemingly no break in sight.

Many parents would like just to be able to take a daily walk alone but are unable to do so, and lack of respite is pressurising the mental health of both carers and the person they care for. Families feel unable to provide the level of meaningful activity that their sons/daughters would otherwise have if they were at school or a day service. Carers are also exhausted taking on the additional role of home-schooling with no breathing space. Many families rely heavily on help from the wider family outside the home, while lockdown has meant this informal support network is no longer available, especially where this is reliant on grandparents.



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A commitment to wider family members is creating huge pressures on carers. With siblings currently at home and frequently taking on a heavier caring burden, parents are stressing the need for respite for them also. Carers feel they are unable to concentrate on other children in the home as their child with learning disabilities requires more attention, therefore the pressures of ‘feeling guilty’ are building up for many families.

Families are anxious to know when they will be able to access respite services after lockdown, and how they may be able to do that safely. Social care services and respite providers need to let families know how they will plan with them for the future. There are concerns over how all forms of respite will be funded and how it can safely continue. There is understanding that there have been some great examples of creative respite happening across Wales in the last few years, and it is time for good practice to be shared. However, there is also real fear that some of these models may now be at risk.

Topics reiterated from families included;

“creative respite through direct payments”

“daily respite/breaks to take a walk alone”

“not anytime away from each other so no breathing space or time to wind down and recover”

“hardest part is being available to other children”

Systems & Services

Direct payments are accessed by many carers in Wales. The Social Services and Well-being (Wales) Act 2014 enabled carers to think more creatively about care and support for both themselves and the person they care for. Direct Payments allow for flexible support ensuring it is meeting individually identified care needs. The current lockdown has meant that a number of carers have had their payments suspended or access to their support paused, leaving them unable to use their DP in a way they did previously. Some families have confirmed that their local authority has supported creative alternative uses for the payments, while others have reported that they’ve been told that there is ‘no service’ until the COVID issues end! This inconsistency of approach is adding to confusion that many carers already feel, and shows issues with inequity creeping in.

Local authorities will clearly need to think differently about the use of Direct Payments in the next few months and support Services and providers will need to be



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enabled to work in partnership with families around flexible working arrangements so that services can still meet agreed outcomes.

One example where Direct Payments continued to provide opportunities includes – *“Direct payments allowing my son to camp in the garden to do his scout badges. Due to us being allowed to employ siblings.”*

We expect to see more examples of Direct Payments being used in this way in the upcoming months if conversations between social care and families are truly co-productive to find appropriate solutions.

Assessments and Care planning

Some carers have had regular contact with their social worker during lockdown to discuss service provision, while others have said they have struggled to reach anyone.

Carers are worried about the pause on assessment processes and how long that will be allowed to go on for. They are also worried about post lockdown assessment processes and how these will be safely carried out. We have heard from carers that care packages agreed before lockdown have been stopped due to the pandemic, with families unable to access any form of support as to when they may be reinstated or how to go about it. It appears that some Social workers have been seconded to other teams within the service to help out with Health issues at the pandemic height, but it's not clear how soon they will return to their substantive posts. This lack of engagement is a critical concern for many families and the individuals they support. Families do not 'blame' social workers for being deployed to other areas, but they do 'miss them' as their key connections.

Education and therapeutic support

Schools' closing has understandably caused huge concern amongst LD families. Whilst many noted the disruption this has caused for their children, many also felt that schools opening again was a concern when families were not sure about the safety implications.

Many families connected to the Forum support children and young people with complex needs, often health related as well as cognitive. As a result, this group has particular concerns around returning to school. Equally though, many families have been in touch with the concern that they do not want their children to unduly suffer as a result of school absence, and that for many, the digital platforms do not work as a teaching tool. They would welcome more pre-recorded lessons and visual teaching aids to be produced and shared online, to help ensure that children remain



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connected to their learning environments. They would also welcome greater engagement with the Education teams at Welsh Government and local authority level, to help design a road map back to school for some of the more disadvantaged children and young people in Wales. At present, they feel this is being mainly discussed between teachers and professionals.

Children who access regular therapies as part of their essential health and well-being needs are now unable to do so. There have been offers to carry some therapeutic interventions online but, although a welcome gesture, this process doesn't fully adapt to meet all people's needs. Families raised concerns over how these therapies will continue in the future and whether they can safely work face to face once again sometime in the near future.

Financial implications for families

We are all aware of the financial implication this pandemic has had on the economy. Many families raising children with additional needs face poverty, due to many being single income households as a result of the caring responsibilities they face. Several families have expressed concerns around security of income from furloughed jobs once the buffer is removed, and also the ability to return to work if their caring responsibilities remain the same. For lots of LD families, being able to work will rely on either schools or community services being open. Therefore, there is a real concern around carers falling through the net in terms of financial poverty.

Families are also concerned how some crucial services will continue to be run if funding is distributed elsewhere under emergency decision making. Many have asked *'how can these services both continue to run and run safely without resources'*? Families are anxious for some reassurance that the community provision, much of which is provided as a partnership between local authorities and the third sector, will still be available to them when lock down lifts.

Comments received include;

"money will be needed elsewhere"

"I am worried that the charities and support groups we have depended on will not still exist after a prolonged lockdown is over, and likewise for businesses we have relied on who have been sympathetic and helpful to us"

"everything will continue to be done over the phone/social media etc. Nobody will be checked up on thoroughly. All appointments will be months' behind. So my child's mental health will suffer"



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All reflect the shared sense of concern about support that will be available post lockdown.

Moving out of lockdown

As we move out of lockdown, it will be critical for Welsh Government to provide information and recovery plans that are practical, clear and as much as possible, **directly co-produced** with individuals and families, in order to ease anxiety for families and their relatives as we move forward. Shared ownership of the recovery will bring both reassurance and also greater confidence of success.

While there has been general understanding and initial sympathies as to why some existing methods of co-production and engagement with Carers' services and forums had to be paused at the start of the pandemic, there are growing concerns around the ongoing lack of engagement with those services as we plan for the future.

Clearly there are still some safety issues and concerns that impact on the ability to engage wider communities via face to face formats. However, as we have now seen many communication methods set up via online technology, it seems prudent to seek to reinstate key groups such as the Regional Partnership Boards, local planning forums and national Welsh Government Ministerial groups to be able to return to some of the key co-productive processes that were set up. This will help to ensure the collective voices of citizens, including carers return to the centre of discussions in preparing a way forward for recovery.

Alongside these, it is clear that carer services, both local and national, will be essential in ensuring family carer voices are heard to support the recovery work that needs to be developed, and instrumental in co-designing actions that will form plans connected to this work.

Essentially, family carers wish to be heard and respected, with many saying they want...

*“somebody to chat to that just gets it”
“somebody to talk to (about what matters)”*

Prior to lockdown issues, many carers felt that some mechanisms did exist, and some network groups have said that they have retained some positive connections with key partners. However, for most families, there is a sense of **feeling left out of the design and decision making processes**, and a real fear that the pandemic will create an accidental consequence of this continuing, Seeing an intended return of



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the ‘*done to*’ culture, instead of the ‘*done with*’ that we have all worked so hard to reach.

The All Wales Forum would like to hope that will not be the case, and that LD family carers, and the wider carer population, will once again be engaged at a strategic level to help shape the answers for so many families that manage under so much pressure day in, day out.

There have been some positive stories too around life in lockdown for families. Many families have created different routines with their sons and daughters learning new skills and sharing solutions with peers. The increased family time has also seen some positives, with free activities such as walking helping with poverty concerns. Also, some families have been able to use their support package more flexibly.

Local carers’ services continue to be a lifeline to families by providing information and also a listening ear. Many local coffee mornings are continuing to be held via online apps like Zoom and Skype which have kept many carers who rely on those support networks less isolated.

However, the positives are understandably outweighed by the wider stresses caused. Carers are the hidden heroes in our society, and they need to be fully recognised as a priority group of people carrying specific risk.

The All Wales Forum of Parents and Carers will continue to work in partnership with key family networks, wider third sector agencies and Welsh Government colleagues to support the critical need to follow the journey of family carers as we transition from lockdown, ensuring that family carers across Wales are being listened to, heard and respected.

Key Recommendations going forward:

- **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.
- **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.



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- **Respite in all its forms – short breaks/creative DP/and day services etc – should be seen as a priority when considering next steps of support;** specifically enabling flexible approaches to the use of Direct Payments.
- **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.

We would like to thank all families who took part in the survey and wider engagement conversations for sharing their stories and providing the information above.

**The AWF team.
May 2020.**