

Children in Wales Plant yng Nghymru

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Speaking with one voice



Also featuring:

- Meic Cymru
- PTC Therapeutics Ltd
- The Sustrans Active Journeys Programme
- Transforming Relationships and Sexuality Education in Wales
- Play Wales

Welcome to the autumn edition of the Children in Wales magazine.

The theme of this edition is Education News and Life After Lockdown, and what a rich theme this has proven to be. We have excellent contributions from the third and statutory sectors, and we also hear from young people too.

Since the full return to school in September, education settings have been faced with the challenges of adapting to new ways of working due to the ongoing threat of COVID-19, whilst coming to grips with the fact that many months of schooling were lost during the lockdown. Of course, these challenges stretch far beyond the school, college or nursery gates, as other service providers and partner organisations play a vital role in supporting our education professionals to meet these challenges head on.

Considerations explored in this edition of the magazine include the impact on the wellbeing of children and young people during the lockdown, and subsequent return to school; the impact on pupil progress and the attainment gap; and lessons learned around digital exclusion.

Of course, in spite of the impact of the pandemic, our education professionals are working tirelessly to develop and implement the most significant reform to our education system in over 30 years, as we work towards delivering the new Curriculum for Wales. Rightly, articles featured in this magazine also discuss issues pertaining to the new curriculum.

It seems to me that the values espoused by the four purposes of the Curriculum for Wales are perhaps even more pertinent for us all, given our ongoing experience of the pandemic.

Owen Evans CEO, Children in Wales



Ceredigion College - Learners Return Sarah Childs, College Counsellor



Whenever there is social upheaval, new language is coined – 'digital poverty' has been one term to have emerged for schools and colleges, and Welsh Government have recognised this and put a substantial amount of funding in to support us to overcome this.

We can all see with our own eyes that things have changed. The physical adaptations have, of course, been a mammoth undertaking, with college campus staff rising to the challenge to fully meet the Covid guidelines to ensure the safety of our learners and staff; we have seen bright yellow tape being put up (and down! on otherwise practical brown carpets) new signage and screens being erected, hand sanitisers all around and furniture being rearranged.

Then there are the hours that tutors have spent getting their courses internet-ready - the transformation of the staff into a highly digitally literate workforce has been astonishing, although not without anxieties for some.

The return to college was a time of great uncertainty, with both tutors and students feeling the pressure of learning a new set of rules and behaviours - would they get the rules wrong? Would they be exposed to Covid? Would they still get their lunch?

A few weeks in, and we're still learning about some of those challenges. Although Ceredigion is

one of the most beautiful places in the country to live, rural poverty has always been an issue for many of our learners, all the more so because it's hidden. Before Covid, some of our students used to go home from college on a Thursday and not see anyone else outside their family until Monday because they live in remote locations, and they don't have access to public transport or are expected to help out at home or on the farm. Adding digital poverty to the mix has not helped the situation.

There are huge variations in internet speeds around Ceredigion. And, as one tutor puts it, you can really see a difference between the 'haves' and the 'have nots.' With the support of the Digital Poverty fund the college is working to ensure that eligible learners are provided with digital equipment such as laptops, earphones and dongles, as well as internet access to ensure that none of our learners are disadvantaged because of rurality or low family income. These are the students who are already facing so many social barriers and, where college has always been a great leveller of opportunity, it's been challenging to prevent those gains being taken away. Tutors have been supported throughout by the college's Teaching and Learning Team to provide training and support on online delivery, and have been able to provide a curriculum which is blended so that learners can enjoy the mix of both online delivery as well as hands-on activities onsite, which is so vitally important in vocational subjects. We have adapted the timetables to ensure that learners are in safe 'bubbles' but that they don't miss out on vital face-to-face tuition in a mix of remote and onsite learning.

Many of our students have embraced the new normal, appreciating the time and money they are saving now they don't have to commute (some of our students live up to two hours away by bus), but the psychological costs are possibly only just emerging.

Editor: Alice Bailey, alice.bailey@childreninwales.org.uk
Children in Wales, 25 Windsor Place Cardiff CF10 3BZ Tel: 029 2034 2434 Website: www.childreninwales.org.uk Twitter: @childreninwales
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After Lockdown: A School's Perspective Helen King, Headteacher, Llantilio Pertholey Church in Wales Primary School, Abergavenny



The effect of the global pandemic and the total lockdown was different for every person and every family. At one end of the spectrum people were bored and found it a challenge to fill the day; at the other end people were working nonstop and barely had time to themselves. Every individual's circumstances came with their own stresses and strains, and many adults struggled to muddle through.

We knew that these extraordinary times would be just as difficult for young people. Teachers across the land were anxious to know how our children (and parents) were coping at home. During these unprecedented times, surrounded by uncertainty, it was important to support families in our community. We kept them informed of the latest COVID-19 developments and rules; planned learning activities for 'homeschool;' telephoned families regularly to offer support; offered childcare in keyworker hub schools and we shared prayers and spiritual support from the diocese.

We understood that our children's experiences through over 100 days of lockdown would be wide-ranging. It was impossible to gauge the impact those experiences would have on wellbeing. Some had a very positive experience, in a safe and pleasurable environment. Isabella (aged 9) described how she 'enjoyed finding new

walks and playing in the woods and spending more time with family.' Some children may have had a challenging or traumatic time over lockdown. Lewis (aged 9) explained how he found it difficult being 'separated from people, friends and family.' Children were aware of others' difficulties, as Noah (aged 9) explains, 'Some adults are having to stop jobs and that meant they wouldn't earn money.' Some children spent most of lockdown in the keyworker HUB school. Some children enjoyed home-school through lockdown. 'My mother is a very good teacher,' declared Nell (aged 10). Others hardly did any school work at all. We tried to reassure parents that we understood and would manage all circumstances.

Children had three days in school in July to catch up with friends and teachers. The usual transition activities that are done when children move into a new class or even a new school were impossible. For some, this 'check in' time was invaluable. Others found it challenging to then be away from school for another six weeks for the summer holidays.

School looks very different now. There are arrows on the floor, warning tape, posters about washing hands and the yard is coned into zones. Although we tried to reassure families with letters home, photographs and a risk assessment of our socialdistancing procedures, we knew that some found returning a worrying prospect. Phillipa (aged 7) explained, 'When I came back to school I was really nervous, but then I was happy straight away.' A member of staff is in the yard to greet every child each morning. Sam (aged 8) describes the scene, 'At school you get to see a lot of smiles.'

That first September morning when we greeted parents and children back was wonderful. The sun was shining and it was delightful to hear voices of children playing again. Some ran excitedly into the yard, grinning from ear to ear. 'I'm SO glad to be back at school because school is awesome,' (Harvey, aged 6). 'I am happy because I get to see my friends,' (Darcy, aged 6). Others were more reluctant. Jack (aged 7) said that, 'I was sad because I didn't want to leave my family, but as soon as I got into school I was happy' and Betsi (also aged 7) told her teacher, 'I like school but I miss my mum.' There were a few tears that morning, and that was just the parents! Other parents looked relieved to finally have a bit of normality back and perhaps a bit of peace and quiet at home.

Supporting children in their wellbeing had to be a priority for us. We gave the children opportunities to share their experiences and to describe what they had enjoyed over lockdown and what they had found difficult. Jack (aged 10) stated 'being back in school is amazing, but I am still worried because COVID-19 is still going on.' Children had clearly missed the routine of school as Amelia (aged 7) explained, 'I like being back at school. You know what you can do and what you can't do.'

Reuben (aged 8) summed it up perfectly, 'I love our school. Seeing my friends, doing lots of work. I feel safe.' How wonderful, what more could a school ask for in these difficult times?





Young Wales Annual Conference

Due to the Coronavirus pandemic, this conference will now be held VIRTUALLY in March 2021.

THE EXACT DATE WILL BE CONFIRMED.

It will focus on some of the key issues facing young people in Wales, and give young people an opportunity to help us refocus the Young Wales priorities for the coming year. This conference will be FREE OF CHARGE and further details about speakers etc will be forthcoming.

RSE Action Group

www.childreninwales.org.uk

Autumn 2020

RSE Action Group

Transforming Relationships and Sexuality Education in Wales Professor EJ Renold and Dr Ester McGeeney, RSE Action Group

Researchers, young people, teachers, and NGOs around the world have long been campaigning to improve sex and relationships education (SRE) because children and young people rarely get the high quality provision they need in schools. Over the past few years, Wales has been making significant progress in this area.

Since education was devolved to the Welsh Government in the 1990s, Wales has sought to embed policy and guidance on sex and relationships education into a social justice model of rights, equity and wellbeing.

In March 2017, Professsor Renold was invited to chair an expert SRE panel established by the Welsh Assembly's Cabinet Secretary for Education, Kirsty Williams. The panel was tasked with reporting on how teachers could be supported to provide high quality sex and relationships education more effectively in schools in Wales, as well as help inform the development of the future curriculum in this area. Drawing on a wide range of national and international research, we found that:

- Current law and guidance on SRE is outdated
- SRE is a basic curriculum area with nonstatutory status, which means it is often poorly resourced and given low priority in schools, leading to uneven and unequal provision
- SRE is rarely LGBTQ+ inclusive and not enough attention is given to rights, equalities, emotions and relationships
- SRE is often inadequate for children and young people with disabilities and additional learning needs
- There is a gap between children and young people's lived experiences of relationships and sexuality (online and offline) and the content of SRE
- There are not enough opportunities for children and young people to influence what they learn in SRE

We also found that high quality SRE is associated with a range of positive and protective outcomes for children, young people and their communities and can:

- Help increase children and young people's understanding of safe, consensual, equitable and positive relationships
- Help reduce homophobic, biphobic and transphobic (HBT) bullying and increase safety and wellbeing for LGBTQ+ children and young people
- Help all young people make informed decisions about sexual intimacy and reproductive health
- Help advance awareness of sex, gender and sexual equality and equity; and gender-based and sexual violence

In our <u>report</u> we used this evidence to map out a series of recommendations to the Welsh Government and outline a vision for a new holistic, inclusive, empowering, rights and equity-based Relationships and Sexuality Education (RSE) curriculum. Key recommendations included that RSE should be made statutory in all schools in Wales, that teachers should receive high quality professional learning on RSE, and that RSE should be guided by core principles and key thematic areas as set out in the report.

In May 2018, Education Minister Kirsty Williams accepted all of the panel's recommendations and changes to the law are in progress to make RSE a statutory subject for all children aged 3 – 16. This is an historic and important change for Wales, but there is much more work to be done. In particular, we need clear guidance about the content and pedagogy required for RSE and resources to train teachers, and give schools time to prepare for the new RSE curriculum. With the necessary legislation, guidance and resource in place schools will have the support that they need to create an inclusive, relevant and empowering curriculum so that all children and young people's diverse needs and experiences can be met and their health and well-being safeguarded, nurtured and supported.

Work is underway. Building on some of the best practice in primary, secondary and special schools in Wales, and internationally, the beginnings of a new mandatory RSE has recently been published in the <u>Curriculum Guidance for Wales</u> as a crosscutting theme.

This guidance states that the new proposed RSE will:

"Aim to gradually empower learners to build the knowledge, skills and ethical values for understanding how relationships, sex, gender and sexuality shape their own and other people's lives.

It will seek to support learners' rights to enjoy equitable, safe, healthy and fulfilling relationships throughout their lives.

This includes the ability to recognise, understand and speak out about discrimination and violence and know how and where to seek support, advice and factual information on a range of RSE issues."

Over the past two years we have been working with the Central and South Consortium to engage 23 schools in RSE professional learning. Each of these schools have conducted a creative audit with their school community to find out what children, staff, parents and governors want and need from the new RSE curriculum.

If you want to out find how these schools have been exploring new ways to co-produce their RSE curriculum with learners, view the film "Making Space: Transforming Relationships and Sexuality Education in Wales" or read the suite of illustrated school case studies which map the learning journeys of primary, secondary and special schools.

And to find out more about how to undertake a creative audit on RSE and other sensitive issues associated with health and wellbeing more widely, and with activities that have been adapted to address the challenges presented by the COVID-19 pandemic, go to: https://neu.org.uk/media/11726/view.

Professor EJ Renold and Dr Ester McGeeney were co-authors of <u>'The Future of the Sex and Relationships Curriculum in Wales'</u> (Welsh Government, 2017). Professor Renold is also chair of the newly formed Wales' RSE Action group.



Year 7s write what they would love to learn in RSE.

The New Curriculum for Wales and the Early Years Sector Hayley Edwards, National Day Nurseries Association Cymru

The Curriculum for Wales is due to be rolled out from September 2022, with early years providers (currently delivering the Foundation Phase) being some of the first to switch to the new curriculum.

This curriculum reform is the first complete reform of education in Wales for 30 years, and is designed as a continuum of learning across all stages. It aims to prepare children to thrive in a future where digital skills, adaptability, and creativity are crucial, rooted in Welsh values and culture. At the heart of the Curriculum for Wales 2022 are the 'Four Purposes,' the aspirations for our children and young people in Wales.

September 2022 may seem like a LONG way off, however it is essential that practitioners are aware of, and prepared for, the changes within the curriculum to ensure that future planning, learning opportunities and environments for learners, will be in alignment with The New Curriculum for Wales and children are offered genuine, authentic, child-led learning experiences.

If the coronavirus pandemic has taught us anything, it has further exhibited how good early years practitioners are at reacting and adapting to a range of challenges in order to gain the best experiences for the children in their care. Providers have continued to achieve the same learning outcomes for children with modification and adaptation of learning spaces and resources. This current process of reviewing and modifying provision, environments and experiences is excellent practice for looking ahead and beginning to consider and implement the new curriculum within early years settings.

The Welsh Government have resumed work on creating additional guidance for pre-progression Step 1 and a Curriculum and Assessment Framework for the non-maintained sector. They have committed to publishing all additional guidance in 2021, with consultation and testing to take place during springtime for final draft publication of the documents to take place in autumn 2021. Allowing the sector a year to engage with and implement the documents ready

for September 2022.

In the lead up to the release of the new documents, and looking ahead to 2021, there are three things that providers can do NOW to prepare for the new Curriculum for Wales 2022, along with free support resources from NDNA Cymru:

- Use the Four Purposes The Four Purposes are the shared vision and aspiration for every child and young person in Wales. All learning decisions within the setting should be in pursuit of the four purposes. Ensuring a secure understanding of the Four Purposes is crucial to a solid foundation for learning within settings. NDNA Cymru Four Purposes-Factsheet
- Support staff Staff will need the skills to teach the new curriculum well. Professor Donaldson describes in detail 12 Pedagogical Principles that underpin the new curriculum. Understanding the individual components will support teams to confidently embed the new curriculum and achieve high-quality learning experiences for children. NDNA Cymru 12 Pedagogical Principles-Factsheet
- Make a plan and review it Audit teams and environments, this will give a realistic idea on where to start, then agree an action plan for progression. When trying out new approaches and strategies, make sure you are measuring and recording the impact on the children's learning

NDNA Cymru have also developed an online training course to support with the underpinning knowledge of the New Curriculum for Wales 2022, and the next steps for practitioners and settings. NDNA Cymru Embedding the Four Purposes- Online training.

Do not be scared of the change! Learning through play and child-led learning remains, and the principles and pedagogy of the new curriculum derive from the Foundation Phase, something that early years practitioners have been doing for years.

The Sustrans Active Journeys Programme: From the school run to activities and resources
Hayley Keohane, Sustrans Cymru



With the new school year in full flow, the <u>Sustrans Active Journeys Programme</u> offers a safer and healthier option for the school run. The programme works with schools across Wales to create a culture that makes it easier for children to walk, scoot or cycle.

Our programme also provides resources and activities for schools in line with the new Curriculum for Wales, adapted to be delivered virtually if necessary.

Returning to school since the pandemic

Many families have been enjoying walking, running, scooting and cycling as part of their daily exercise during lockdown. As children return to the classroom, the school run provides a great opportunity to keep this going.

With many schools staggering arrival and departure times, active travel can reduce busy drop-off bays and create a safer environment for both children and parents. Our Active Journeys team can help support schools implement the Schools Streets scheme. School streets creates a temporary restriction on traffic at school drop-off and pick-up times. This ensures more space for active travellers to socially distance outside of the school gates. Sustrans worked in partnership with Newport City Council to run a Street Trial at St David's RC Primary School. This community-led process transformed the road layout outside the school, reducing congestion and creating a safer school street.

Blended learning

Our Active Journeys team are busy adapting school activities and lessons, focused on active travel for delivery under new local lockdowns and Covid-19 restrictions. A blended learning

approach is being adopted by our dedicated Active Journey officers. Classroom activities can be delivered virtually, and Sustrans assemblies are being recorded and streamed online.

Virtual delivery will support face to face activities such as Dr Bike workshops, adhering to social distance guidance. Additional safety and hygiene measures have been put in place to keep our team, the children, and staff safe during school visits

The new Welsh Curriculum

Activities and lessons delivered as part of our Active Journeys Programme are being developed in line with the new Welsh Curriculum. The activities offered can help schools deliver on the four purposes of the new curriculum.

Our sustainable travel lessons help learners to become ethical, informed citizens of Wales and the world. We can teach children about the decarbonisation of their school streets and the role they can play in using active travel to reduce air pollution. Our activities help build children's confidence to walk, scoot or cycle to school. This aims to develop healthy, confident individuals who take part in physical activity and understand the impact of exercise on physical and mental health in their daily lives.

The new curriculum's Health and Wellbeing Area of Learning and Experience is addressed in our Active Journeys Programme, by building enthusiasm and skills amongst children to support new active travel habits. Walking, scooting or cycling to school is a fun and healthy way to support children's physical and mental wellbeing.

Amidst growing support for cycling on the national curriculum, a recent survey suggests that 4 in 5 parents want cycling lessons in schools. Active Journeys can offer training and support to schools, families and communities to incorporate walking, scooting or cycling into daily school life.

Don't miss out on our advice for <u>families</u> and <u>schools</u> returning actively and safely to schools post-lockdown. Find out more about how school children in your communities could benefit from the Active Journeys Programme and how to apply <u>here</u>.

Questions, Questions and more Questions Ffion-Haf Davies, Year 13 Student, Ysgol Gyfun Gwyr

A giant question mark has loomed over the heads of young people since March this year. A question mark over our 2020 exams. A question mark over the new academic year. A question mark over a second wave. A question mark over 2021 exams. Questions, questions and more questions. Our lives seem to be shrouded in uncertainty, yet we're seen as a scapegoat.

When your life has always been measured in school days, homework assignments and tests, to suddenly have these disappear is a shock. Our computers became our only companions, the infamous ping of Teams notifications the new school bell. Despite the hardest efforts of our teachers to keep some semblance of normality, nothing was the same. When you're sitting in the same place all day, every day, motivation zaps out of you. A task that would normally take half an hour would now take two as we were surrounded by distractions.

Once the announcement that exams were being cancelled broke, I cried. It's a strange almost melodramatic sounding statement. However, as a year 12 student at the time I wanted an opportunity to prove myself and to put myself in good stead for year 13. However, we as year 12s were left in the lurch. We had no idea for weeks what would happen to our grades in the summer. Were we to sit our exams later in the year? Would we have to sit them the same time as our A Levels? Would we receive predicted grades? The wait was agonising as we sat in a no-man's land, clinging to every rumour that floated by like life buoys until we finally found out our fate.

After months of nothing but a fleeting visit to school in July, it was summer. Our Teams notifications silenced; a sense of normality resumed. Restrictions began to lift, and we were allowed to meet our friends at a distance, to go shopping, to 'Eat Out to Help Out.' We were allowed a sense of freedom we hadn't experienced for months. But then came results day where young people's grades across Wales were unfairly marked down. After all the stress we'd been through this was another unnecessary hurdle.

Nobody can argue that this year hasn't been unprecedented, yet A Level and GCSE students

knew that our grades would be predicted back in March, therefore we were all left reeling how this could be allowed to happen.

As a year 13 student I'm heading into one of the most important years of my life, as I juggle A Level work, university applications and the impending threat of the pandemic. Year 13 is a stressful year at the best of times, however, as the pandemic worsens and year groups begin to isolate, our education is again being disrupted. There's a constant uncertainty over if, or more likely, when, we'll have to isolate. When we'll have to miss another batch of school. The question on all our lips is whether we'll sit exams next summer?

Every young person in Wales will have had a different experience during lockdown and we'll have missed varying amounts of classroom time. I can't imagine not sitting my A Levels in the summer. However it doesn't feel fair that some of us will have had hours more contact than others. As a result, teachers are setting more homework and tests than ever to ensure plenty of evidence, if the worst happens again. As young people we're all keenly aware of the power of every single mark; each piece of work is no longer just a practice for an exam, it could possibly dictate our grade in the summer, adding an extra layer of pressure to young people across Wales.

The past six months have undoubtedly taken a toll on everybody, both physically and mentally. As young people who probably didn't even know what a pandemic was this time last year we've had to adapt to a whole new way of learning, whilst grappling with constant uncertainties. It feels like we're being blamed for a rise in cases as we try to understand all the conflicting regulations; we're allowed to spend all day less than two meters away from our friends in school, yet the moment we step outside the school gates it's illegal.

2020 hasn't been easy, but all we ask for is a little clarity and to be taken seriously. We have questions and we'd like some answers.

Elena Ruddy, Year 11 Student, Ysgol Gyfun Gwyr

This time last year, had you asked secondary school students what their biggest worry was, the commonest answers would probably have been schoolwork, or friends, or external exams.

This year, it's a different story.

Living in a world of COVID-19 offers brand new challenges for a generation of young people to overcome. Having missed four months of their education to lockdown, most schools are still playing catch-up — a huge challenge.

In the wake of the pandemic schools have had to make dramatic changes. From class seating arrangements to the canteen and the buses, the changes are visible everywhere, in every aspect of school life. One-way systems can be found on every campus – often you might have to walk in circles for 10 minutes to reach classrooms that are less than a hundred yards from your starting point. The school fields and yards have been split into eighths to ensure that every student stays within their own 'bubble.' If there is a case, 'only' 300 students or so will be forced to isolate - a total of 600 school weeks lost as a result of one positive test.

This is our new world, one of uncertainty for many students. Thousands are studying towards exams that may not even take place, and some have come to secondary school without being able to meet a single student outside of their year. At the other end of school life, many more have left their school forever without having the chance to say goodbye – traditions like signing shirts and leavers' assemblies will be a real loss to many students, who will more than likely never see some of their contemporaries ever again as they go on to different secondary schools, colleges, universities or to the workplace.

Each pupil has different feelings about returning to school. For some it is a welcome escape from family, and a chance to see friends for the first time since March. For others it is troubling to know that they are back in the midst of crowds, putting vulnerable family members at risk. Returning has also been a shock to the system for many who had grown used to lie-ins over the summer!

As the government extends restrictions to fight a second wave of COVID-19, we are repeatedly told that schools will remain open at almost all costs.

Not many would dispute that keeping children in school should be our absolute priority. Children have already suffered an educational disaster, losing four months of schooling. Plus it's not just about education, it's about school as a safe space for many and children's mental health. We can almost all agree on that.

But it is simply not enough to pronounce loftily that schools will be 'prioritised' and stay open come what may. This ambition must be backed up by a workable plan.

At the start of term almost my entire class came down with a nasty cold. A couple managed to get tested (negative), but many others had to miss school. They had associated coughs, but couldn't get the all-clear from a test, which at that time was only available 60 miles away.

Meanwhile another entire year group at school has had to stay at home for two weeks because of a positive case, as well as all the children on the affected pupil's bus. Of course, our school is far from the only one affected. Public Health Wales says that since 1 September, a total of 298 pupils and 279 staff had received a positive Covid-19 test result from 344 schools across Wales. It is estimated that in North Wales alone, more than 1,500 staff and pupils are currently self-isolating.

We are barely into autumn. Is it realistic to think that schools can limp through to spring in this fashion? Research is said to show that schools are not a driver of infection as they are with flu, but with flu, we don't normally send whole year groups home on the basis of one case. While there is an appreciable level of Covid-19 in the community, children in schools will repeatedly be found to be infected, whole classes and bus-loads of children will miss weeks and weeks of school and suffer such severe stop-start disruption that they cannot possibly prepare for exams. This is quite aside from the risk of catching Covid-19 at school. No wonder pupils are worried.

It is a stressful time for everyone, and the pandemic has completely changed our way of life. We have had to rethink all aspects of our lives, and the effects on schools have been farreaching and severe. There is little doubt that these experiences will be vivid in our memories for years to come.

Pembrokeshire & Ceredigion Young Carers

www.childreninwales.org.uk

Autumn 2020

PTC Therapeutics Ltd

Tales from the frontline Vikki Phillips, Pembrokeshire & Ceredigion Young Carers, Action for Children

What issues and challenges have the young carers from Pembrokeshire and Ceredigion Young Carers faced as a direct result of Covid-19?

Lockdown has been extremely challenging for everyone in society, none more so than the young carers in Pembrokeshire and Ceredigion. They have raised interesting issues, unique to young carers.

This already vulnerable group has had to deal with the stress of avoiding contracting the disease like everyone else, but also ensuring the family members they support are safe and supported. That meant buying food and supplies in the midst of widespread panic buying, keeping education going for themselves and siblings, and doing whatever they could do to protect the family's wellbeing.

Ensuring our vital services continued was and remains a challenge. Despite working from home, we have provided food vouchers and wellbeing packs, and we are always available on the phone. We also conduct one-to-one support and group sessions on Skype.

The support sessions have unearthed a number of issues that have developed as the pandemic and its attendant restrictions ebbed and flowed. In the early days of lockdown, some young carers were reluctant to let carers into their homes for fear of the virus being transmitted to family members.

Then, as schools reopened after the summer, group and 1-2-1 sessions drew very mixed responses about being back in school. There was a lot of fear around catching Covid-19 and bringing it home to other family members. One young carer told me that the social distancing in their school lasted a day and now they don't know what they can and can't do. Some are also confused because they turn 11 soon and the rules change for them again. The majority are happy to be back and seeing friends, but then they don't understand why they can't meet up outside of school.

Samantha (name changed) is a good example of the sort of issues that young carers have faced. She is a 12-year-old young carer in our Pembroke Dock group that cares for her mother who suffers with multiple health issues, including mental health. The family were shielding during

lockdown and have not been able to visit any day centres. They managed to look after themselves and decided not to let carers into the home as they were anxious about others bringing in the Covid-19 virus.

She told me: 'Before going back to school I was looking forward to a normal routine again, seeing teachers and friends. But I was worried my friends wouldn't wear masks so that I could possibly bring the virus home with me.

My main worry was leaving my mum during the school day. I didn't want her doing too much or end up feeling lonely. We've had six months of not being reliant on others for care and suddenly we had to get outside help again. We were anxious that someone else would bring the virus to our house and make us ill. Then there was the chance I could bring it home from school. I've enjoyed being back, but I still look forward to getting home and making sure mum is okay.'

Samantha's mum added: 'I want her to go to school and enjoy it. I try not to pass on my anxieties to her, she shouldn't have to worry about me, but she does.'

Such stories are not unusual, and the young carers have benefitted from sharing their situations with their peers who understand what they're going through. We continue to support, encourage and signpost other avenues of support, ever watchful of these new issues as they arise. The responsibility on these young people was already considerable, but Covid-19 has introduced a whole host of new issues to deal with, making our support more important than ever.

Pembrokeshire and Ceredigion Young Carer services supports young carers aged 8 – 25 by raising awareness, identifying and providing direct support to children and young people who look after or help to look after someone in their family who is unwell or disabled, including children caring for parents who have mental health or substance misuse problems.

Recognising the signs & symptoms of a rare condition: Aromatic L-Amino Acid Decarboxylase (AADC) Deficiencies Catherine Dulku, PTC Therapeutics Ltd

What is AADC Deficiency?

AADC deficiency is a rare genetic disorder that affects the brain, causes abnormal muscle tone, and affects how a child develops. AADC deficiency may be the underlying cause for the clinical features suggestive of Cerebral Palsy (CP) or epilepsy.

AADC deficiency is very rare. Because it is so rare, and because the symptoms are similar to symptoms of other diseases, including cerebral palsy or epilepsy, diagnosis can be difficult.

Certain symptoms increase suspicion for AADC deficiency, including the combined presence of decreased muscle tone, delayed motor development, movement disorders, and autonomic symptoms (eg, nasal congestion, excessive sweating).1

AADC deficiency is a disorder that interferes with the way the cells in the nervous system talk to each other through substances called neurotransmitters. In AADC deficiency, a genetic mutation (change in a gene) leads to a decrease in the amount of neurotransmitters made.

The age of symptom onset is typically within the first year of life, with the average patient showing symptoms at 2.7 months of age. Because patients with AADC deficiency present with a range of mild to severe symptoms, some patients may present later in life owing to milder symptoms.1-3

Despite a young age of symptom onset, the mean age of diagnosis is 3.5 years. One reason for this is that the clinical presentation of AADC deficiency can be similar to other more common neurological conditions (e.g. CP, epilepsy, and other Paediatric neurotransmitter disorders). 2,4,5 Because of the shared symptoms between these conditions, patients with AADC deficiency can often be misdiagnosed.4-6

There is presently no cure for AADC deficiency, but there are Standard of Care Guidelines that have been developed to help manage AADC deficiency.⁷

Signs and Symptoms Autonomic Dysfunctions

The autonomic system is the part of the nervous system that acts largely unconsciously to regulate bodily functions, such as heart rate, body temperature, and respiratory rate. Autonomic dysfunctions can include ptosis (drooping eyelids), excessive sweating, and nasal congestion. Patients with AADC deficiency and Paediatric neurotransmitter disorders may experience

autonomic dysfunction.2, 8, 9

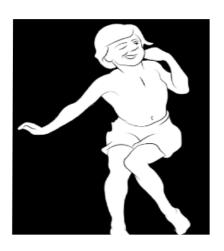
Developmental Delay

Developmental delay is when a child does not reach their developmental milestones at the expected times. This can include a child lagging behind its peers in terms of cognitive/thinking skills, social and emotional skills, speech and language skills, fine and gross motor skills, and/or daily living activities.10

Children with AADC deficiency, CP, and neurotransmitter disorders may experience developmental delay.2, 11, 8#

Dyskinesia

Dyskinesia is an impairment in performing voluntary movements. Patients with dyskinesia uncontrollably move their head, arm, or leg.11 Patients with AADC deficiency and movement disorders may experience dyskinesia. 2,11



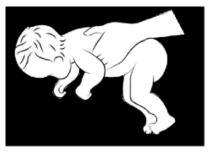
Dystonia

Dystonia is a disorder of abnormal muscle contractions that produce repetitive involuntary twisting movements and abnormal posturing of the neck, trunk, face, and extremities. 13 In addition to AADC deficiency, other conditions associated with dystonia include movement disorders (eg, CP), mitochondrial disorders, and other neurotransmitter disorders. 2, 11, 8, 13



Hypotonia

Hypotonia is a loss of muscle tone.12 Children with hypotonia typically show little to no movement when held facing down. In addition to AADC deficiency, hypotonia may be seen in movement disorders (e.g. Cerebral Palsy mitochondrial disorders, and other neurotransmitter disorders.1, 11, 8, 13



Child exhibits 'normal' posture



Child hangs in upside down "U" with little or no movement. movement

Oculogyric Crises

Oculogyric crises are acute, involuntary reactions of the ocular (eye) muscles, resulting in involuntary movements of the eyeballs into a fixed position, usually upwards,in both eyes.14 Additional manifestations of oculogyric crises may include backward and lateral (side) flexions of the neck, tongue protrusion, and jaw spasms. The typical duration is several seconds to hours.14 Oculogyric crises may help differentiate AADC as these eye movements are not seen in CP, epilepsy, mitochondrial disorders or other movement disorders.2, 13



Seizures

A seizure is a sudden, uncontrolled electrical disturbance in the brain that can cause changes in movement or behaviour. 15 Some seizures can look similar to a patient with AADC deficiency. Patients with AADC deficiency and CP may experience seizures. 2, 15 Patients with epilepsy experience

recurrent seizures. 15



The Challenge of a Correct Diagnosis

Many of the most common symptoms of AADC deficiency can be misdiagnosed as several more common conditions such as cerebral palsy and epilepsy, resulting in potential misdiagnosis,16,7,17,18 Symptoms may be misdiagnosed as:7,17,18 Oculogyric crisis→ Epilepsy/seizure, Mitochondrial disease. Dystonia, rigidity, motor delay→ Cerebral palsy. Hypotonia, akinesia, ptosis→ Neuromuscular disorder.

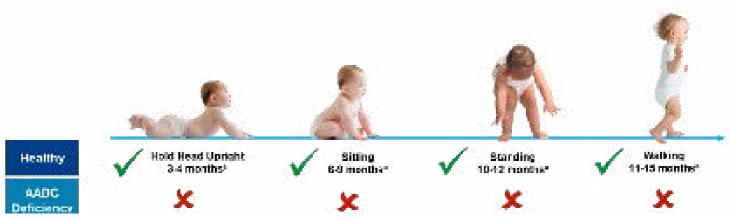
In a clinical study of 78 patients who were diagnosed with AADC deficiency, the following symptoms were documented:16

- Hypotonia was present in 95% of patients, the most commonly reported symptom₁₆
- Developmental Delay was exhibited in 63% of patients, including impairments in head control, sitting, crawling or standing and speech delays.
- Oculogyric Crises occurred in 86% of patients.
 Patients also presented with movement disorders₁₆
- Normal Electroencephalogram and failure to resolve seizures with antiepileptic medication are important clues to distinguish oculogyric crises from seizures₁₆

Normal EEG and neuroimaging; one study showed that only a small proportion of patients with AADC deficiency had an abnormal EEG (Electroencephalogram) MRI (Magnetic Resonance Imaging), or CT`16 (Computerized Tomography Scan).

The following account is from a carer of a child who was diagnosed with AADCd:

"...We knew from early on that something was wrong with our son Oscar. He was born full term, and at first everything seemed normal. He was fussy and had some trouble feeding at first, but we chalked it up to the normal rigors of parenting a newborn, like we had experienced with our son Sam. But it seemed to take forever for Oscar to achieve any of his milestones. He didn't hold his head up until he was about six months old,



and he didn't sit up until he was a year old. Even then, we had to help him stay upright. We saw a couple of Paediatricians who brushed us off, but finally found one who would listen.

The doctor gave Oscar a thorough physical and noted the missed milestones along with a lot of muscle weakness, which might explain why Oscar couldn't sit up on his own. The doctor said Oscar might have cerebral palsy and ran some tests, including some brain imaging. The results came back with some abnormalities, so the doctor recommended physiotherapy. After a year of physical and occupational therapy we started to see mild improvements in Oscar's muscle strength, and he was even able to walk a few steps with some help by the time he was two. But he still had a lot of muscle weakness, and he started to have these spells where he would just look up at the ceiling. They didn't seem to bother him, but they were scary, especially for his brother Sam.

At this point Oscar was three years old, and the spells were getting more frequent. He hadn't made any more progress with the therapists, so we saw a paediatric neurologist. The doctor did another exam and asked us a lot of questions about whether we had family members with similar experiences or if I'd had a difficult pregnancy or delivery. We told him everything had been fine. The doctor looked over the brain scans and said he wasn't sure cerebral palsy was the right diagnosis. He saw one of Oscar's spells while we were in the office and said Oscar might have a problem with his neurotransmitters. The doctor suggested taking blood and urine samples to run some screening tests. He wanted to narrow down the possible diagnoses.

The tests came back with some elevated levels that the doctor said indicated a neurotransmitter disease. To confirm the diagnosis, he said we'd have to do some more invasive tests. Oscar had a bout of

pneumonia that landed him in the hospital, so we had to wait until he was better to do the tests. The doctor took more blood for an enzyme test and a genetic test, and we gave permission to do a lumbar puncture. Those were the worst moments of my life, having to hold down my screaming child while they stuck a needle in his back.

The results came back after a few weeks. It turned out that Oscar had a disease called AADC deficiency. The results of the lumbar puncture showed that Oscar's neurotransmitter metabolites indicated he had this disease. It was confirmed by a test on his blood that showed his AADC enzyme wasn't working. The genetic test showed a mutation in Oscar's genes that the doctor hadn't seen before. But he said this information, along with the enzyme test, and the lumbar puncture results confirmed the diagnosis. We finally had a name for Oscar's condition.

Getting an Early Diagnosis

AADC is challenging to diagnose due to the complex nature of its presentation, and the signs and symptoms which resemble other conditions, such as Cerebral Palsy and epilepsy. This is a life-limiting condition with no known cure. Management is through a multi-disciplinary team approach.

In 2017, consensus guidelines7 were published, giving management and treatment options, both pharmacological and non-pharmacological, to help manage AADC deficiency. Therefore, it is vital that children receive the correct diagnosis so that they and their families can access the appropriate management and support.

If you have any concerns, please speak with the parents and then direct them to their HCP

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This disease awareness article has been initiated and funded by PTC Therapeutics. EE/AADC/UK/20/0044. Date of Preparation: September 2020.

Study highlights teacher concerns, wider challenges and recommendations for any future lockdowns
Sarah Toomey, HAPPEN Primary School Network



Since lockdown, the HAPPEN Primary School Network Wales, based in Swansea University, has been carrying out research to gain a better understanding of the impact of Covid-19 on the health and wellbeing of primary school pupils and school staff in Wales, to help inform decision making.

Initially, HAPPEN asked primary school pupils (aged 8 – 12) to take part in their 'HAPPEN at Home Survey,' to understand and identify the impact of lockdown on young people's health and wellbeing. Then, with the reopening of schools in June, HAPPEN introduced the 'Return to School Survey' to gather opinions of staff on their experiences of returning to school.

The survey was completed by 211 primary school staff, including headteachers, teachers, teaching assistants and support staff across Wales. Due to the timing and rapid response required before school return, a report was produced in August 2020 to relay initial findings and staff views.

Children need to be in school

Initial findings indicated that staff felt that children needed to be back in school for their education and social development, but the survey highlighted that staff had serious concerns.

Concerns over pupil and staff health and wellbeing

A large majority of health and wellbeing concerns expressed by school staff were regarding the health implications of virus transmission. Specific worries were expressed by those shielding or living with vulnerable people.

Concerns over pupils' health and wellbeing were discussed primarily with indirect effects of the virus, such as the impact of lockdown on children's

emotional health and the challenges supporting this on return to school. This was discussed in terms of variation and inequalities in the home learning experience.

Staff also emphasised concerns over the mental health and wellbeing of the school staff. The challenges of balancing work, family life and childcare commitments were remarked upon by many. Headteachers especially were concerned over staff sickness and problems with staff shortages and budgets if staff have to self-isolate.

Challenges supporting children to progress with learning

Teachers felt that there was a huge variation in terms of the impact of lockdown on children. Whilst the positive impacts for some children were commented on by teachers, many staff were concerned about a lack of learning progression during the lockdown period for some children.

School staff expressed concerns over staffing, and the potential lack of time within the classroom setting to dedicate to those pupils who they feel have been disadvantaged in their learning by the lockdown. The Covid-19 situation forced the need for smaller class sizes and many reflected on the positives of this in terms of a positive impact on their learning and social skills.

It was felt by staff that resuming normal school routine would be a challenge. Concerns were raised over ensuring the effective running of the school day and maintaining new practices, including cleaning and hygiene whilst delivering the curriculum.

Another challenge relayed was the ability to teach effectively at a social distance. This was felt to be a particular concern for those teaching

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Foundation Phase pupils.

Recommendations for return and any potential future lockdowns

Staff identified the need for greater support for wellbeing for pupils and staff, with some suggesting smaller class sizes would help in enhancing both learning and wellbeing. Some staff also commented on the need to prioritise pupil's health and wellbeing before assessment of attainment.

With regards to suggestions for a future potential lockdown, primary school staff highlighted the importance of building rapport with parents, with some recommending more direct communication between teachers and parents and emphasised that communication with parents should be an ongoing process.

The need for better communication over the scientific evidence, as well as the need for more regular virus testing, was raised. Some staff called for greater transparency over statistics and evidence and less mixed messages.

Staff suggestions

- "Support in regards to mental health and wellbeing, possibly reduced class sizes, extra support for pastoral care and to help catch up"
- "Maybe designated staff in each school to help with wellbeing?"
- "Clear guidance as to expectations in terms of

- managing the virus and the learning experiences that the children can take part in"
- "Welsh Government need to address teacher anxiety. We need to know that our health is also a priority"

Professor Sinead Brophy, Director of NCPHWR and lead Researcher at HAPPEN, said: "Our survey showed that school staff need clear information in time to act. They have real concerns around health and well-being, both for staff themselves and their pupils."

Charlotte Todd, Researcher at HAPPEN, added: "Clear priorities for the way forward also emerge from the survey including greater investment into the wellbeing of both teachers and pupils and clearer guidance and communication at all levels."

HAPPEN aims to bring together education, health and research to help schools have a better understanding of pupils' physical, psychological, emotional and social health. HAPPEN is part of the National Centre for Population Health and Wellbeing Research (NCPHWR). NCPHWR is funded by the Welsh Government through Health and Care Research Wales.

Find out more about HAPPEN and their ongoing COVID-related research on their website: www.happen-wales.co.uk

school approach to supporting health and wellbeing provide an environment, facilities and space to play, socialise and relax at break times. It raises concerns that when schools can't or don't provide these, pupils are less physically active and can find it hard to relax during playtimes, which affects their wellbeing.

At about the same time, Play Wales noted an increase in parents getting in touch with concerns about the shortening of school days which resulted in reduced playtime, and also, the withdrawal of it as part of behaviour management policy. Due to these concerns, increased queries and to respond to Estyn's report, we published A play friendly school – Guidance for a whole school approach for schools so that children can enjoy sufficient playtimes as part of their school day.

The right to play

All children need to play. Children have a right to play, as recognised in Article 31 of the United Nations Convention on the Rights of the Child (UNCRC). Playing is one of the most immediate and important aspects of children's lives – they value the time, freedom and quality spaces to play.

As an indication of the significance the United Nations places on children's play it has published General Comment number 17 on Article 31. This is an official statement that elaborates on the meaning of an aspect of the UNCRC that requires further interpretation or emphasis. The General Comment defines play as children doing as they wish in their own time and in their own way. It has the key characteristics of fun, uncertainty, challenge, flexibility and non-productivity.

schools have a major role to play. This includes through the provision of outdoor and indoor spaces that afford opportunities for all forms of playing and for all children, and that the structure of the school day should allow sufficient time and space for play.

Children's opportunities for playing in all settings are dependent on a wide range of issues, which are arranged across three themes of:

- Permission: fear, expectations, tolerance, and the way adults view childhood and play
- Space: the amount, design and management of space
- Time: how time is structured and the obligations children have on their time

The Play Wales guidance provides policy and practice-related information to help school communities take a whole school approach to support children's right to play, addressing the three conditions of permission, space and time for play. Designed to enhance the good work already being done to provide better play opportunities in school, it aims to make everyone's time at school happier and healthier. The guidance is summarised in 15 steps to a play friendly school and provides tools to implement them.

The demands on schools to achieve academic targets must not be put above the duty to protect the health and well-being of the pupils in their care. Time and space allocated to play is associated with pupil wellbeing and should, therefore, be considered as a positive element of school life.

A <u>play friendly school – Guidance for a whole school approach</u> is freely available on the <u>Play Wales website.</u>

Promoting, providing and protecting playtime Marianne Mannello, Assistant Director, Play Wales

Play Wales is the national charity for children's play in Wales. We campaign for a play-friendly Wales and champion every child's right to play.

In 2019, before the coronavirus pandemic, Play Wales alongside partners, educational psychologists and researchers contributed to the development of a position statement for the British Psychological Society. It highlights the importance of play in helping children deal with uncertainty and challenge, regulate emotions and experience fun, enjoyment and freedom.

Playing:

- Helps to give children a feeling of normality and joy during an experience of loss, isolation and trauma
- Helps children to overcome emotional pain and regain control over their lives

- Helps children make meaning of what has happened to them, and enable them to experience fun and enjoyment
- Offers children an opportunity to explore their own creativity

During lockdown and the subsequent easing of restrictions, there have been calls for schools to prioritise play as part of recovery and transition back to formal education. Children's rights advocates are calling for the focus to be on play and mental health, rather than 'curriculum catch-up.'

In summer 2019, Estyn published the Healthy and happy – school impact on pupils' health and wellbeing report, which evaluated how well primary and secondary schools in Wales support the health and well-being of their pupils. It noted the importance of school play and break times. The report highlighted that schools that apply a whole

The General Comment specifically states that

New Welsh advice services for those in need Citizens Advice Cyrmu

Advicelink Cymru is a new Citizens Advice-led service for Wales. The service is designed to help people most in need of advice services, particularly those who would not usually seek advice, such as carers.

Advicelink Cymru has a central focus on partnerships, linking together different organisations, including Carers Wales, to provide free, impartial and quality-assured advice and wraparound support.

Key features of Advicelink Cymru:

Provides quality-assured advice on welfare benefits, debt, employment, housing, discrimination and education. Reaches out to people, through partners such as Carers Wales, to get advice to those most in need of them before they are in crisis. Works in a joined-up way so that getting advice is as simple as possible.

Case study: Securing financial support for a carer and young person

Louise is a lone parent of a disabled young person. Disability Living Allowance (DLA) was paid until a decision was made that Personal Independence Payment (PIP) was not payable. In addition to the financial loss of DLA, other linked benefit entitlements were stopped.

Louise contacted Advicelink Cymru after it was noted that the PIP decision had not been changed. We supported Louise to collate additional evidence, and an adviser prepared a written submission to the Tribunal.

16 months after the original decision and six months after our submission, the DWP changed the PIP decision in Louise's favour. Louise gained additional income of £300 per week and backdated payments of £18,000.



Louise told us, 'The loss of income and the delay in dealing with the appeal led us into a terrible financial situation and we are so grateful for your help; the back payments came just in time to help us avoid getting very seriously into debt.'

How we can help

If you need advice on welfare benefits, debt, employment, housing, discrimination or education, please call Advicelink Cymru services on 03444 77 20 20 or by textphone on 18001 03444 111 445. For further information about the service, please email: advicelinkcymru@citizensadvice.org.uk

Children in Wales

ildren in Wales Winter Magazine callout

The National Lockdown was a difficult time for everyone and had a huge impact on the lives of children and young people. During this time, the Meic helpline was there, providing support with any issue that they needed help with.

Returning to school does not mean that their concerns have disappeared, and judging from helpline contacts in this period, Covid-19 has had an effect on anxiety and mental health issues in children and young people. Over the last few weeks, the Meic team has been concentrating on raising awareness of the service to coincide with students returning to educational establishments across Wales.

Meic has been in contact with the four regional education consortia in Wales requesting that they share information about the helpline service and the resources available with schools. We told them about the resources available to professionals on Meic and the lesson plans on Hwb.

In October, Meic will be running a Back to School campaign gathering the views and experiences of children and young people who returned to school in September. The campaign will start with a short survey being promoted across social media channels with approximately 10 questions being asked about being back and how they are feeling. All those who complete the survey will be entered into our prize draw.

The information gathered from this survey will inform the rest of the campaign content. A video will be created sharing results from the survey and a series of articles will be created for the website, addressing any issues or worries that arise from the survey. The Meic advisors will be made aware of the findings keeping them on top of young people's concerns. The results of the survey and campaign will be shared with you in a future issue.

Children in Wales Winter Magazine callout

Our Winter magazine's theme will be **Supporting the Emotional Health and Wellbeing of our children and young people during lockdown and Covid-19**, and we welcome content from our members. We would be particularly interested in receiving articles from professionals, around:

- *What are the psychological effects of Covid-19 on children and young people?
- *What can be done do avoid anxiety and other illnesses?
- *How your service users are coping and have you had to adapt your provision?
- *What mental health services and helplines are available?

And, more importantly, it would be wonderful to hear from the children and young people you work with/are involved with. How are they coping (or not) with self-isolating because of an outbreak in school, or another period of school closure, and the effects on their emotinoal health and wellbeing?

Articles should be between 500 and 750 words; be available in English and Welsh and have a title and author. One good quality JPEG photo can be included.

The deadline for articles will be Thursday, 17 December 2020.

Please get in touch if you are interested by emailing louise.oneill@childreninwales.org.uk



Meic's Back to School Campaign