

Ceri Reed, Parents Voices in Wales - Advocating For Your Child

Welcome to neurodivergence and advocating for your child and young person. Parents Voices in Wales is a social enterprise company. We were established in 2018 through my lived experience of the disconnect between families, education and services. I was very frustrated that I couldn't have my voice shared in the support that my child required at the time and I couldn't understand why we weren't working more collaboratively with schools in order to meet needs. Also the reason why my child had to hit a mental health crisis before we could get any support. So that led me to setting up Parents Voices and advocating for families whose children have neurodivergent conditions and/or mental health challenges. Parents Voices is an all Wales based company. We're an online community predominantly. Everybody is welcome to attend who's a parent and carer of a neurodivergent child. It's a safe space for parents and carers. Somewhere that you we can help you navigate the system. There's advice, but also we have in-person get togethers now like coffee mornings and afternoons for autistic, ADHD and neurodivergent parents across Wales in Cwmbran, Newport, Bridgend and Cardiff. So keep an eye on our public social media pages for those advertisement. And please join us and find your neurokin. So we work across the whole system to improve the outcomes for additional learning needs and neurodivergent children, and I'll talk a little bit in a while about the difference between that language between ALN and Neurodivergence. We help schools improve their school inclusion procedures in the classroom. We help train school consortia, we sit on the Welsh Government's Neurodivergence Ministerial Advisory Group in order to upskill the autism code of practise to a neurodivergent code of practise, and we undertake parent and Carer co-production in neurodevelopment and CAMS in health boards across Wales. Our mission is to ensure that children and young people and adults have early help and enhanced support on a needs-led basis, to prevent poor outcomes. And that is where we need to really understand that language of what is Neurodiversity and what is neurodivergent.

So neurodiversity is a term that was coined by an Australian sociologist in in the 1990s where she was writing a dissertation and wanted to reflect a paradigm of human difference. Her name is Judy Singer and she related it to the biodiversity of plants,

where in our Natural History every plant has a function and a purpose, and irrespective of what it looks like or what those strengths are, they contribute to the equilibrium of our nature. So Judy wanted to reflect that in the neuroscience of the cognitive and physical purpose and strengths of humans. That forged the start of a neurodiversity movement where we look at inclusion, where everybody has a place in society, everybody matters irrespective of their needs or irrespective of their strengths. Everybody is included now in order for people to thrive. We need to be able to identify those strengths, but when people have needs and they're not being met and they're facing challenges, they tend to not show their strengths because they're struggling. So what the neurodiversity movement wants to see is much more inclusion within the workspace, within schools, within services, within the whole system, so that people have their needs met. And then when we protect those peoples' well-being, we harness those strengths and that becomes their purpose and their main identity. So neurodivergent people are people who have notable differences between their strengths and challenges. Neurotypical people are people that don't have notable differences between their strengths and challenges. So for example, somebody who is dyslexic, for example, may have great verbal skills and language skills, but will struggle to read and write. And that is a notable difference between their strengths and challenges. The neurodiversity movement calls for a strength-focused approach where we don't judge somebody by their challenges. That isn't a deficit, it's just difference and what we do is we meet those needs for that person and we harness the many strengths that that person can bring to the table. So what happens is when we identify strengths and talent, we improve well-being and purpose, but we create aspirations and this is really important for children who have learning differences. We can create aspirations for them and put them on the pathway where they can see hope for the future and have a goal in their learning of "these are my strengths and this is what I want to be when I grow up."

So one in five learners have learning differences and that could be characteristics of ADHD, autism, dyslexia, dyspraxia, dyscalculia, foetal alcohol syndrome, pathological demand avoidance, learning disability. There are an array of what we would call neurodivergent conditions, however historically children have had to meet a threshold of severity in those characteristics before they can obtain a diagnosis. And some children were not able to receive a diagnosis. And then there was no support. So historically in education, when we were in our previous SEN Policy Framework, children

couldn't get any support if they weren't severe enough, and this is why Parents Voices were set up because we know that children might have differences and may not meet that threshold for diagnosis, but they still need support. What the research and clinical academics and research across Wales and the world have shown is that neurodivergent people can have invariably 2 or more neurodivergent conditions, and it might be that they have one condition like ADHD that meets the threshold for diagnosis and they might have a few more conditions that are sub threshold for diagnosis. Or they could have two or more conditions that don't meet the diagnostic levels at all. So we have historically, as well in our medical model, diagnosed people through a single lens where you were just autistic or just dyslexic. But Professor Amanda Kirby, who's a leading neurodiversity movement researcher, her research has shown that co-occurrence of conditions is the rule and not the exception. So the majority of people have two or more conditions, and we know that one in five learners think and learn differently. That's 20% of the population and the majority of children and young people have an average to high IQ. Now historically we've always associated a learning disability with autism, but we now know that the majority of autistic children, young people and adults do not have a learning disability. But under the umbrella of neurodiversity, everybody is included. Parents Voices in Wales tends to shine a light on the children and young people who are in mainstream who haven't been identified. Where they are subthreshold for diagnosis, or they may have one. So although Neurodivergence includes everybody, we tend to focus a bit more on the majority that don't have a learning disability because there hasn't been any third sector in Wales to that point that was shining a light on these children. We know that those with more complex and severe needs will be identified and on the ALN register in schools and more likely - not always, but more likely to have an individual development plan, but many children who haven't been identified and are not on the ALN register or are not receiving support in school are often termed 'the missing middle'. The 'missing middle' are the children who don't meet the threshold assessment or diagnosis in either neurodevelopmental services or CAMHS services and we know that these children are more likely to experience anxiety-based school-related absence, depression and self harm or they might be supported in one area of their differences but not in the other. We know that from research undertaken in 2021 by Professor Anne John that the majority of learners who experience emotional-based school avoidance were neurodivergent. And we also know that if they are not supported and they're not in school, there is a

risk of poor outcomes for them. So we advocate for a robust, needs-led, inclusive environment in schools to cater for all learners, whether they have a diagnosis or not.

When we talk about the missing middle, I want to just use this visual analogy that's created by Professor Amanda Kirby of Dolt solutions. Amanda talks about Neurodivergence being a bit like balls in a bucket. So if we look at the first bucket on the left hand side, you can see different coloured balls and each ball represents a characteristic of neurodivergence. So for example, the dark red ball might be dyslexia, the pale red ball might be dyspraxia, and the pale blue balls, of which there are many, might be ADHD. So the more balls that you have, the more characteristics you have of that condition and that means you meet the threshold for diagnosis where that line is across the bucket. So for this learner, they may have ADHD, but with milder characteristics of other neurodivergent conditions. And historically, they would only get support for the ADHD. But at least they would be on the ALN register for having ADHD. So if we look at the middle bucket, you can see that there are many balls that represent stronger characteristics in a variety of areas, but none of them meet the threshold for diagnosis. Now this learner would be called the 'missing middle' and this learner wouldn't be receiving any support at all historically, and may not even now in the current ALN, get an IDP or may even be missed completely. This is why we need to make sure that our classrooms and our services are inclusive and cater for learning differences and not be label-led.

Why is that important? Why do we need to be needs led? Well, there's a extensive research about the link between neurodivergence and trauma, and together that pushes children and young people down the mental health spectrum to mental health challenges. In fact, Professor Helen Minis, who is a researcher in the University of Glasgow, undertook research, because she couldn't understand why some children who had experienced trauma in her cohort went on to have poor mental health, where the other 50% of the children and young people who would experience similar or same trauma didn't, and what she found was that the Neurodivergent children were not only 10 times more likely to experience trauma, but they were more likely to experience poor mental health because they carry a heavier load at the outset from being neurodivergent. So Professor Anita Thapar at the Wolfson Centre, her research also shows that poor mental health is an accumulation of social stresses. For example, neurodivergence, trauma, poverty, bullying and so on. So if you have a neurodivergent

child, we have to make sure that we reduce those social stresses as much as possible because they will otherwise have a much higher risk of travelling down that mental health spectrum to poor mental health. We've talked earlier about Professor Anne John's paper, about neurodivergence and low attenders, and how that is linked to poor mental health and we also undertook a survey in 2021 with Doctor Tony Lloyd of the ADHD Foundation where we had 900 participants, which showed that 65% of children and young people on the CAMHS waiting lists were neurodivergent or seeking assessment. So it's important to reduce the load for these learners in meeting needs early and we can't do that alone. As parents and carers we try our best, but we can't do it alone, it takes a village, it takes a whole system. It means that we need the support from schools, we need the support from services. We need to know what's available to us in our communities from third sector so that we can build a nest around our children and reduce the risks of poor mental health challenges, school avoidance, et cetera. So it's really important that our schools work closely with the CAMHS in-reach teams, the early help services such as the Family First services and 3rd sector, that that whole system comes around that school community. And the fact that the school staff get trained in identifying them. We're not asking them to be clinicians, we're asking them to be able to identify the signs of neurodivergence or poor mental health challenges and trauma as early as possible and then refer them to the appropriate services. But we need to be able to stipulate that the needs of a child come into three main headings, the emotional, social and educational needs. And ESTYN now highlights the needs for schools to collaborate with parents and carers in co-producing a plan for their neurodivergent children. So we've now seen the justification for that needs-led approach, because we need to stop pulling people out of the river. We need to stop, go upstream, and find out why they're falling in. And I mean, we need to stop children from entering the CAMHS system. We need to go upstream in schools and at homes and prevent them from falling into the system.

So what is a needs-led approach and what is the United Nations Convention on the Rights of the Child relating to this? Well, a needs-led approach is impacted by the culture of a school, it really is, and if the culture of a school is nurturing and is focused on safe and trusted relationships, then the approaches are relational, trauma-informed and inclusive. You will naturally have a universal support for all learners and needs-led approach. It also does require, however, an understanding of neurodivergence that one in five learners will think and learn differently. It also requires schools to

understand what a needs-led approach looks like, and that is also the same for mental health services. We need to have more neuroinclusive therapies such as EMDR and DBT, more accessible in our communities and not just concentrated in specialist services. We need to have neurodivergent inclusive support early on. So universal support is effective when we have a good culture at the school and when we have a good understanding of neurodivergence and we know at the moment with the ALN reform that schools, some schools are doing brilliantly, other schools are on a journey and they need support to get there. So, universal support is about supporting everybody. It is equality and if we get it right, it helps us to meet the needs of 'missing middle' learners, those that may have several neurodivergent conditions that aren't severe enough to meet diagnostic level, but it requires relational approaches, psychologically informed environments. Remember neurodivergence often overlaps with trauma. We need adults to co-regulate with our learners to make sure that we can keep those learners calm. We can do this by teaching from an early age, from primary school early years to secondary school, how to undertake self regulation? How to undertake grounding techniques at times in a day when a child might be most dysregulated, like entering school, entering a busy classroom they can undertake inclusive classrooms. So for example, they could give an overview, a visual overview of what's going to happen in the lesson, recap every 20 minutes of what they've done and where they're going, and then consolidating at the end to give context to newer divergent learners, to help them stay in the room with their learning. Very often there's an overlap of presentation in challenges with different conditions, such as developmental language disorder, dyspraxia, dyslexia, ADHD, and autism, in the ability to break down tasks, in the ability for time management. In ADHD, for example, some children may be time blind, and so the use of visual timers in the classroom can be really helpful. Breaking down tasks for just 10 minutes and then having a break and reflecting on what they've done can be really helpful. Helping children to understand instructions - auditory processing is very common presentation across a number of conditions and so writing instructions on the whiteboard can be really helpful and making sure that that you know those instructions are written in the same place on the whiteboard every lesson. Providing vocabulary list or topic words that could be sent home, for example at the beginning of a term, so the parents and carers can go over those with the learner. We could incorporate frequent movement breaks every 20 to 30 minutes in school, just so those kinesthetic learners and those with ADHD, for example, are able to move, because we know that they learn with movement access, for example, to sensory toys

and papers and pens for doodling. So some children learn better when they're stimming or when they're doodling. Gentle prompts and watching our language when we need to prompt a child in class so we don't humiliate or embarrass them. Starting and completing tasks. Support writing with mind maps - not every child can write well if they have dysgraphia or dyslexia or ADHD, and they might need an iPad. So assistive technology where it's needed, along with vocabulary lists and maybe letting children write notes with mind maps is much more easier than having to write reams and reams of narrative. And to consider the chairs and the seating for peer support and regulation. I know that from experience for us that a child our child with ADHD would struggle sitting next to another child with ADHD because they would trigger each other. So making sure that the child is sitting somewhere they they're happy to sit and they feel supported by the peer next to them and they can remain regulated for the lesson. So these are just some typical examples which are touching the surface, the tip of the iceberg. We should be doing in our inclusive classrooms and when it comes to additional learning provision, this is the next stage.

This is the next step where some neurodivergent learners need more than just the Universal Provision, and parents are finding it in some areas difficult to get this Additional Learning Provision without an IDP, but on a needs led-approach it should be arranged. So I recommend you going back to the ALNCo and asking for a team around the child or team around the family, or just have a conversation about what you think your child needs above universal support, what would make the difference? And we've actually got a resource on our website, Parents Voices in Wales called the Pupil Voice, which you can print off, download and complete and take that to a meeting at school. It helps you kind of form a solution rather than going to school with a problem. And remember the additional learning provision may be flexible because your child changes as they go through. That's the beauty of Additional Learning Provision, is that it can change on a needs add basis. You're not stuck with it for a year and it will be reviewed in 12 months, a bit like an IDP, it's very flexible. So it's a step up step down approach on a needs-led basis. It might be that you require shared access to classroom support for a teaching assistant that should be available to you with additional learning provision. With the problems that we have at the moment with staffing, with some schools losing teaching assistants, the shared approach is probably the best move forward now in making sure that we support as many learners as we can in the class because when we're looking at statistically, you've got 6

neurodivergent children in every class of 30. You know you should be able to access assistive technology should you need it with additional learning provision, you don't need an IDP for that. Perhaps your child would benefit, especially in secondary schools if they're going to do GCSEs with additional study sessions as small group work, and that can sometimes happen in primary school. And that was a bit like school action, where they would have extra sessions so that you shouldn't need an IDP for Additional Learning Provision. And sometimes it's the simplest things like the flexible start and finish times if transitions are a problem for a child. Or maybe they struggle to do a full week and they need that little bit of flexibility. You know, have those conversations. Be needs-led. It might be that they require peer mentoring at break time. You know, if you don't know what's on offer, ask the school. It's not a secret menu. It should be a transparent menu so that you can see what's available for your child. Often an exit pass could be really helpful and do the additional needs provision where a child can leave for movement breaks, so they can self-manage their regulation or maybe go to a sensory quiet space to do some grounding or decompress. And remember that once you set this in motion you evaluate it regularly. You monitor it week by week, what needs to change, what needs to adapt on a graduated response. You will know because your child will show that they're not happy, that they're not regulated and that would be your red flag to review. Are you meeting the needs adequately? Is it now time to progress to an IDP? So the IDPs are in transition from the statements in September 22 and that's been run over three to four years. It is a legislative document. It is in the ALN code that children with additional learning needs can access an IDP, but it's a long, arduous process. The schools don't want to go down that route because of the level of paperwork and the time. So it's much easier for the schools to provide you with Additional Learning Provision without an IDP. I've had three neurodivergent children and we've managed to get through that without an IDP, but it does depend again on the culture of your school, the expertise of the ALNCo, and the relationships that you have with the school as well in that dialogue. The IDP can be really helpful for more severe and complex profiles and it should include a multidisciplinary team. You should be having an annual review. But as I said, it is a long process and it often requires the child to receive a diagnosis so that they meet that threshold of severity. So the impact on the parents waiting for an IDP or if there's a disparity in opinion between the family and the school, it can be really stressful. So you have children who will be on the ALN register and are called additional in need and you will have children

that haven't been identified who are neurodivergent and called the missing middle and so the approach with the needs-led approach is that we cater for all.

And when we look at this in terms of equality and equity, the Universal Support means it's the same provision for everybody, and that's equality. But some children need more because equality disadvantages them. The universal support is a disadvantage to them, and that is when they need Additional Learning Provision and that provides equity, and some learners will thrive with a robust universal support. But some will not. And we have to underline this, that equity meets the rights of the child on an individual basis.

So the Rights of the Child is a legally binding agreement which protects the human rights of children up to the age of 18 years. It was adopted in 1989, and Welsh Government formally adopted it in 2004. You can access this from the [Children's Commissioner for Wales website](#) and they have information about what are the rights for the child, for parents and carers. So go and have a look at that. But there are 42 articles within the UNCRC and it's underpinned by 4 core principles: There should be no discrimination for any child; we should work as a whole system in the best interest of the child; the child has the right to life and survival and develop to their full potential and of course; and, most importantly, the child has a right to be heard. And in Article 27 of the rights of the child, it states that children and young people should be able to live in a way that helps them reach their physical, mental, spiritual, moral, social potential and the Rights of the Child is underpinning the ALN reform and the whole school approach. And so the schools have a legal obligation to meet these the rights of the child under these articles.

So again, the rights are underpinning the ALN reform and and the school is obligated to meet these through the Additional Learning Needs and Tribunal Wales Act and that states that schools need to help learners as early as possible. Remember, we want to prevent poor mental health outcomes, so we have to provide a needs-led approach early to reach their full potential based on their individual needs. They have a legal obligation to involve the children and the families and Co developing individual plans. And that the ALN reform is a legal document which stipulates that professionals must consider the rights of the child when they make decisions.

So let's have a look now at advocacy, communication and language. Why is advocacy so important? Well, you're the parent. You're the carer. Children and young people cannot advocate for themselves. They may not be verbal. They may have a learning disability. Even if they're neurotypical and thriving, they may not have the understanding of their needs. And they need us. They need trusted adults or parents to speak on their behalf. And we have to advocate to make sure that they thrive in those environments and if they are not thriving, then we know their needs are not being met. So children have the right to thrive at home and in school, in terms of their emotional well-being, their social experiences, their education and ability to learn, the spiritual and cultural well-being. And again, as I highlighted before, it's really important that we use the pupil voice, the voice of the child, to share their needs as well. And in the Pupil Voice resource that we've got on our website, it underlines it really underlines that and when I talk about the whole school approach here, I'm talking about everybody in the school, not the well-being policy. I'm talking about the whole school having a shared language and understanding of why parents need to advocate what the needs are of the child, what neurodivergence is. Understanding the early help prevents poor mental health. And so advocacy is important because we all need to know that neurodivergent trauma can lead to poor mental health, that some learners will not meet the threshold for diagnosis, that we need robust understanding on what our needs, LED approaches and the importance of relationships in school. But that involves us as parents as well. It's not just down to the school.

And I just want to touch on the school's perspective because in any relationship there is the serve and return. We go to them saying "look, we need your help" and we can get frustrated when we don't get what we need for our child and it can cause...well, we're going to talk a little bit more about that in the next slide. But I just want you to walk in the shoes of the school because if we want them to have empathy and understanding about us, then we should also in any kind of balanced relationship, we should walk in the shoes of them and have a balanced understanding and empathise with them as well. So what is the culture of the school? And, when you're dealing with staff, what are they going through? What's the well-being of the staff, the culture of culture of the school can impact the well-being of the staff themselves, you know, on whether that is a healthy culture within the school. What number of students do they have that have additional needs or experiencing self-harm or eating disorders who are not in school due to school avoidance? What number of students are they dealing with

that? And what about if they don't really have a deep knowledge about neurodivergence and ALN and maybe they don't hold the knowledge about your child that you hold? You know, you're the experts in your child. How can you support them in getting to know the needs about your child? And what if the school doesn't have a workplace inclusion plan? Or maybe the whole school approach for the staff is still on a journey? You know this ALN reform and the whole school approach didn't happen overnight. It takes time to embed. So we're looking for a better culture in schools where the staff well-being is being catered for. We know that relationships with parents, we've got a [blog](#) on our site that we wrote with Catrina Lowry and that's all about the impact of poor relationships on teaching staff. It really does impact their mental health. So we do want better relationships because they want to get the best out of us and our child. We want the best out of them and our relationships can create either a positive or negative ripple effect. And they are also led by the school policies which are framed by the culture of the school and in time, what we want to see is school policies being developed in relational approaches and trauma, reformed approaches and inclusion. We're not there yet. Some primary schools I know are undertaking that, but it would be lovely to see that across the whole of mandatory education, up to further education as well. But they are required to work collaboratively with us. But that will depend on the quality of the relationships with the families and if you have a positive relationship with that school, that will then allow you to have that dialogue.

From a parent and carer perspective, the disparities in presentation between home and school - when your child presents differently in school and they see a different child to the child that you know and love and want to support, the relationships can become strained. It's so frustrating when you need to convince people that spend more hours a day with your child than you, that there's something going on underneath and you know what is it? What can you do to help it? But if we walk in their shoes, it's difficult for them if they don't see it. You can also feel a lot of frustration with extended waiting times for neurodevelopmental services, and where's the support when you are waiting for that assessment, or if you're on the CAMHS waiting list, or if perhaps you're on a waiting list for school support. And the helplessness that parents feel can be really significant. A couple of years ago, we undertook a survey in our Parents Voices Group. And we found that 100% of parents reported stress because their child was struggling and 76% of parents had actually gone to the GP for mental

health support because frustration leads to depression, right? It's another social stressor on us that's pushing us down that mental health spectrum. We also know that parents were giving up work so that they could stay at home to look after their child. Or they were missing days in work or they had to go part time, so 48% had a reduced income from caring for that learner. Now that needs to change. OK, because this then becomes a societal and economic problem. So what we would suggest to you is to find those community groups like Parents Voices in Wales. And there's other local groups as well that are that are amazing and do amazing work. So you are not isolated. You are not alone. The lived experience of other parents can share their experience. Success stories to help you navigate the system. But what's important for you to know is that Wales is in a great place right now on the journey that we're embedding a culture shift across Wales to meet the needs, emotional and learning needs of learners early. Wales is embedding the [NEST/NYTH](#) framework, so please go to the Welsh Government website and have a look at that. This framework was co-produced with parents, with Parents Voices in Wales for CYP and it's about multidisciplinary services coming around the family at any time that that child or the parents of that child or the wider family are struggling, and that also aligns to the whole school approach. So it's coming in early, preventing poor outcomes and meeting needs early. And the ALN reform is overlapping with that. It should be seamless. But again, we're on a journey there. Positive relationships benefit our well-being, so the relationships you have with school, the relationships you have with services, the impact on them. So we all need to have a seat at the table. We all need to have an equal voice. We need to address that power imbalance that we often come across as parents and carers and the NEST/NYTH framework and the whole school approach is about addressing that, making sure that you can elevate the voice of the parent and carer, empower them to have a say at what's right for their child.

So let's have a think about communication and what we can do to be constructive when we get that seat at the table. First of all you need to shelve the frustration. However justified you are, however, frustrated you are, and I've been there. Believe me, I've been there. However frustrated you are and angry you are, nobody wants to work with an angry parent. Nobody wants to work with somebody who they can't have a dialogue with, even if it's justified. Right? You need to meet them professionally, and that means by planning your communication, don't ring or telephone when you're dysregulated or when you're upset. We've all done it. I've done it myself, and it's OK

to go back and say "look, I'm really sorry. I was really upset at the time" but remember they might have a number of students that have got ALN and neurodivergent. They'll have a number of staff that are off, the schools are struggling with their economy at the moment. So let's take it down a step. So let's get what we need from schools by working positively with them. So plan your communication. Think about what you need from them and what do they need to know from you to provide that support. It could be, for example, that the universal support isn't robust enough, or it could be that your child needs an Additional Learning Provision. What do you need from them and what do they need to know from you in order to provide that support? And you can break that down under emotional, social and educational headings. Emails are great because it's time efficient. You can copy in the relevant teachers or the relevant service and staff. You have a paper trail the teach the staff can read that at a convenient time for them, and they're much more likely to respond to that, than be able to reply to a phone call, because obviously phone calls can go on and on and on, can't they? But when you send an e-mail, consider whether is this urgent? Does this need to be completed this week or is this something that I could leave for a couple of weeks? Schools have allowances to respond to emails. It can be up to a couple of weeks, so if it's urgent you just need to say "please could I have a response by such and such a date?" Take into consideration the number of learners, the staffing problems that they have at the moment. Just consider is this something that can wait for a week? The other important point to do in your is make sure that you are you contacting the right person. Who is that point of contact in that? So if there's no point in talking, emailing the ALENCo if you want to talk about history or PE. But what you could do is speak to the teacher directly or e-mail the teacher directly or the point of contact that you've been assigned and copy into that e-mail, the relevant people that you want to know about that information. But remember - work with people where you have a positive relationship because when you have a positive relationship, you're more likely to have a positive dialogue. So build on what is strong. It's OK to say to the school "would it be OK if I could e-mail such and such a person, because I feel that I have a positive relationship with them." That's absolutely fine. I'm not saying that they'll agree to it, but it's absolutely fine. And does your child have somebody who they consider a trusted adult at the school? Can that person be your child's advocate in when you are not there? So, for example, it might be a TA. Is that somebody that you could speak to at drop off? The trusted adult with the child, somebody that gets it for you and your child, somebody that can speak on your child's behalf and meet their needs or speak to the

appropriate people at the school? It's always a really good idea to work from the child's perspective. Sometimes schools have pastoral staff and they will be assigned to that year group or to that child. Sometimes that chemistry doesn't work between that adult and the child, and it's OK to say "I'm sorry my child works better with this other person. I don't mean to offend you, but is that OK?" That's all right. Just say it nicely and you know and think about do you require support? So if you're going into meetings, do you need help writing emails? You could ask somebody in the parent group to come and support you. Do you need adjustments for you? You know, if you're neurodivergent - 70% of our parents are neurodivergent, who have neurodivergent children. So do you need adjustments? Do you ask the school for appointment reminders? Do you need an agenda before the meeting? Do you need to know who's going to the meeting and their purpose and their role in that meeting? Are the school using inclusive communication, so it's OK to ask for adjustments for you as well because this is a whole school approach.

And the power of language, I mean, we could talk all day on each of these slides, but we're just scratching the surface across the board here. But the power of language is an important one. And we've talked about positive relationships with the school, allowing us to show appreciation and empathy for the school models to them that we expect that same level of respect as well. When there's a relationship breakdown between a school and a parent or a member of staff, the respect goes, and you have a power imbalance. And if you don't have a respectful dynamic, how can you have a dialogue to meet your child's needs? So we have to walk in their shoes. If there's disparities between home and school, our language is important. Don't be furious, be curious. Say "I understand what my child's presentation is in school, but perhaps we could meet and discuss, as I'm concerned about this situation worsening for them, from what I see at home." Just consider your language when you write those emails, and sometimes when you write an e-mail you can delete things in terms of language and rewrite them to make sure that you are preserving that respectful dynamic. When your child is receiving isolations and exclusions, it's so emotive, it's so upsetting and as well as very damaging for the child. In some detentions, isolations, exclusions they can use restorative approaches, which looks at what happened before that incident. And they talk the child through it. Now, that's absolutely fine, but it needs to be inclusive and what we don't want to be doing is using restorative justice approaches with children that have impulsive behaviours due to ADHD, because we're gaslighting

them then and you can't stop a child from being impulsive by telling them to stop being impulsive. So behaviour is not at a diagnosis. We know that there's been a lot of school exclusions post COVID. And some of those 25 or 30% of those will be labelled disruptive behaviour. Not a diagnosis, so we need that approach to the school to appreciate - I understand that my child's behaviour must have been concerning. However, could we sit down and have a look at my child's needs? Could we look at what happened in the day leading up to that trigger that caused them to behave in that way, and what support can we put in in school to keep them regulated now? Poor behaviour is a sign of an unmet need. Sometimes yes, it can be down to challenging behaviour. I'm just going to leave it as behaviour is a sign of an unmet need- a symptom. So we need to scratch the surface and see what's going on underneath. Are there any neurodivergences there? Trauma? Are there mental health issues? What's happening? Is the child struggling socially? Are they struggling in in the classroom? What are the triggers? It's not just the trigger that is the problem, it's what's happened leading up to that trigger and what's happening in terms of their needs. So I just want you to sit down and have a think about that and work it out with the school. And again, look at the Pupil Voice resource that we've got on the website. And when you are putting in strategies for a child, identify a trusted adult. Especially if they're at risk of isolation and exclusion, please identify a trusted adult at the school that they can build a relationship with, that they can go to when they need to be regulated. Somebody that can advocate for their needs through the school day, but you have to meet the child where they are. They can't go from being dysregulated to 100% attendance and you know it's a slow process and you build on that trust. And it's small steps. So as parents, your role in meeting having the needs met of your child is being a collaborator, but also a strategist because if you're a strategist, you can navigate that on behalf of your child. You're not trying to resolve all these issues in one go, it's small steps. It's a process. It's a journey, and something that's done through a dialogue of positive relationships.

And when we talk about language as well, it's really important that we don't identify these neurodivergent children or these children on the ALN register by their behaviour. You know, how do we as parents, how do services and teachers describe learners? "They're bossy"- well, a trauma informed approach wouldn't call them bossy. It would say "they prefer to lead. They want to be a leader." "They're attention seeking" - you would use instead "they seek connection" and you would describe a child by their

strengths, from home to school. So don't ever describe a child as "talkative" - you could say "I know my child enjoys communicating. I know my child is articulate." "My child is oppositional." – "My child needs to be free flowing. My child benefits from regulated safe relationships." So in the words of Karen Treisman, a wonderful psychologist, "don't make their worst characteristic their main identity." Always describe your child by their needs and not by their challenges. And just to touch on IDPs, it's important that the language in your IDPs cover specifics, so don't allow your IDP to be open to interpretation. Make sure you stipulate specifics. What are the needs of the child? List them. What does that look like in practise? Name the staff by role and specialism, not by the individual staff. And make sure that you identify what that role is with the staff. Ensure that you use the pupil voice when you're filling in your IDP. What does the child want? Make sure you elevate that. Give the time allocation of the specific role or specialism of staff. What are the arrangements in their absence, should they be off sick or they change jobs? What's the back up plan to support the needs of a child? Make sure you stipulate specifics with the interventions, days and times of therapies. How are the school and services monitoring the intervention and the IDP? What is the plan of action when you evaluate the outcomes from that? Because when you evaluate it, if it doesn't work, you need to adapt those interventions. So how often are you going to monitor? Well, you're going to monitor all the time, but how often are you going to evaluate and how often are you going to have a meeting to discuss the outcomes of evaluation? And you need to be able to request details in advance of the annual review. If you don't have any conversation with the school before the annual view, it might be that you don't need it because everything's going well and your child's happy and you're happy with the support. Great, but for some people, that won't be the case. Make sure that you have a pre annual review discussion with the ALENCo because you will not have much time in that annual review to troubleshoot any problems, so ask for a noted meeting, ask to be included in emails and discussions with services. And have a pre meeting or a phone call about any concerns that you have prior to the annual review.

And language at home. You know, this is something that I was guilty of. And I've had to flip that narrative in order to 'sell' school, if you like, to my child when he was really struggling in primary. Avoid that negative language about school. Remember that, as a clinical psychologist called Liz Gregory said, parental anxiety is infectious and also when we get anxious or we're upset about an incident that happened in school, we

can join that child's chaos. We say "that's awful. Oh, I'm going to have a word..." OK. We need to stop doing that because we need to be able to be a team with the school, and we need to be able to show to the child that we're all singing off the same song sheet. Even if you're on a journey and you're not quite there yet, the child doesn't need to know that. They don't need to know that there's cracks in that relationship or there's cracks in that co-production of a plan. So avoid negative language at home. You can say "that must have been very unpleasant for you today. I can't imagine how that felt, but maybe that staff, maybe that teacher had a bad day themselves. Maybe they weren't feeling well. And I'm sure that they didn't mean to upset you the way they did." Try and rationalise if you can, as much as you can, because you don't want to frame school as an unsafe place. We can't encourage those that don't want to go to school. If we're saying negative things about the place, right? So our language can impact their perception of school. Karen Traisman talks about creating ripples or waves, and I want you to think about that when you're talking about school. Are you creating ripples or you creating dramatic waves? We'll try and show that the school is a safe place, that they do care for them, and the one thing that I did for my child, which was really helpful was when I spoke about the child's team, I named the staff and the people from hospital or the people from school, and I said that they're all under Team Fred. These are the people in Team Fred - I'm in Team Fred. You're in team Fred. And you can even have a visual on their bedroom wall or at home somewhere. So they feel held, they feel seen and they feel heard when they're not in school. And that's really helpful. And you can show that to school and they can continue that dialogue with the child when they're in school. So there's that consistency in that relationship. And maybe spend time reflecting with your child about positive experiences they've had in school and the positive achievements that they had thinking about it. Remember that time when you did really well in art? Remember when you did well in that that sport day? Remember when you had that wonderful party? Thinking about positive experiences because this isn't the end journey for them. They're going through a difficult time and you're going through a difficult time, but this this is just a dip in their life, they are going to find that what their needs are. They are going to identify their strengths because you're going to highlight their strengths to them and you're going to highlight their strengths to the school. This isn't your final destination. Don't catastrophize. You are going to get through this even when you feel that you're not, you are going to and it might be that they get educated at home or have alternative provision education, but you are going to get through this. And also embedding that

self belief – “that was really difficult for you going into school today. But you did it” rather than saying “oh, we’ve only gone in for three for two days this week, can’t we can’t we go in for three more?” We’ve all done it. I’ve done it myself, but it’s much better to say “you went in for two days this week and that was really difficult for you. But you did it.” And remembering that when we model to our children, we are modelling how we want them to be, how we want them to manage problems. So it might be that you start vocalising problems that you’re experiencing through the day – “I had a really difficult conversation with somebody today, but oh wow, I’m sure it’ll be OK tomorrow” or “I decided to go and talk to them about it. And I said X, Y and Z and it’s all OK now.” And not only mirroring your language and your problem solving, but mirroring yourself, regulation, emotional regulation, and when we mirror our regulation to a child, where we mirror how we can cope with stressful situations. It helps them to not become dysregulated, and they call that co-regulation. So when we mirror positive regulated behaviours. They will copy us because of the mirror neurons that they have in their brain.

So co-regulation. Neurodivergent families, we carry a heavier load of differences. OK, we might experience differences socially. Some neurodivergent people will really struggle with emotional regulation where we can go from 0 to 100 very quickly, or get very stressed because of the sensory input around us. Or it might be for a variety of reasons that people have a reduced window of tolerance. They struggle to be regulated. They get stressed very easily. They could feel dysregulated very easily. And that’s because we carry a heavier load. And what we want to do with co-regulation is we don’t want the kids to copy that, that ability to get stressed really easily, that ability to get angry really easily. We don’t want them to blow up. We want to increase their window of tolerance. We want to reduce their anxiety at baseline. So what we need to do is start mirroring calm, so start modelling calm using positive language and when we start modelling regulation you’ll notice within a few...it’s a skill to learn and you won’t always get it right. Because as I said, seven out of 10 of us are neurodivergent ourselves. You won’t always get it right, but it’s a skill to learn and it gets better over time and what happens is you find your child becomes more regulated. And when your child becomes more regulated and you’re both regulated, you’re able to start having more constructive dialogue with them and they’re able to tell you then what their needs are, what their opinions are, and you’re able then to share that with the school and Co regulate with the school and relate the needs to them. So, doctor Pookie

Knightsmith has got a great podcast and a webinar on YouTube and on her website on [co-regulation](#) and [window of tolerance](#). Please, please go and listen to it and watch it. It's a game changer and what she says is - you lower the voice. You talk more softly and you talk more slowly. And the reason is when people are dysregulated, their auditory processing is often impacted and dysregulation impacts the functioning of the prefrontal cortex, so they will not hear. They will struggle to have conversations with you. So what we want to do is lower the voice, we talk more slowly. We think about the sensory noise and the light in our environment, making our house calm as possible. And there's a whole different presentation that can be done on psychologically informed environments to support. The external sensory input for children who are neurodivergent or have experienced trauma. [Studio 3](#) is another third sector organisation that undertakes low arousal techniques and they do webinars for families and they talk about considering your body language, stepping on the back foot, keeping your body open, don't cross your arms because children will see communication as much as hear it. So keeping your body open, arms down to your sides, palms facing frontwards, especially if they're dysregulated. Watching your facial expression, keeping it relaxed. Thinking about the words you use, modelling calmness, if you're struggling to remain regulated in triggering situations, walk away, come back. Remember it's a skill to be learned, but co-regulation is something that should be undertaken by adults at home and school, and I have had to tell our school previously that if a teacher would shout at my child, that would be a trigger for them to become dysregulated. So instead of you just saying "my child benefits from coregulation and positive relationships", if that's what your child needs, remember to tell the school so that that support for that learner is seamless home to school.

How to advocate for your child? We've talked about relationships, we've talked about communication - positive language relationships leads to a dialogue and that leads to a needs-led approach for your child. So how we communicate and what we communicate will be central to the process and examples of that could be: socially you could say "is there any peer mentoring support for my child because they feel unsafe during break times, they're at risk of bullying?" Or "could my child please have a safe space at break time where they can be calm and regulated because playgrounds and dinner halls can be really loud and triggering for a lot of neurodivergent children." We know that a lot of neurodivergent children are at risk of bullying, so what is the school's anti-bullying policy? Are there any anti-bullying interventions? We need to make these

learning provisions. This should be a universal approach for neurodivergent children on a needs-led basis. Sometimes kids won't go to school because they worry about the toileting. OK, So what access do you have? "Can my child have an exit pass or a key to use a toilet or a staff toilet because they struggle with IBS or other toileting issues and they're frightened of needing the toilet during school time?" So, you know, you can overcome barriers by having a positive relationship and positive dialogue with the school. When you're thinking about emotional, it could be "can my child have an exit pass to regulate if they need to go to a sensory room or a quiet space?" Could they go and see their trusted adult at any time and have open access to that person, should they feel they have worries or concerns? Can that trusted adult advocate for my child while they're in school? Can my child have access to counselling or can they see the trusted adult while they're on the waiting list for counselling? Could you teach my child's self regulation? And of course, you could only teach a child's self regulation when the child is in a trusted relationship and they're regulated and the adult is regulated. Does every learner have an opportunity to share their worries? You know, is there a space? Is there group work that they can go to? There used to be sessions in school called Talk About which were absolutely brilliant. I know that some people say that it's linked to ABA, but actually the nuance of this talk about was about how to manage social problems and manage to difficult situations for neurodivergent children. And it was really helpful. So speak to your ALENCo about any group work that they might have available. Your child is daydreaming. Could you provide some gentle prompting to help them stay on task, please? Your child is fidgeting all the time, they don't keep still - oh, I think my child is a kinaesthetic learner. Perhaps you could organise some movement breaks every 20 minutes, or send them on an errand to get the registers. Or maybe we could have flash breaks, or just give them a couple of minutes every now and again. Or maybe they need to stim and have a fidget toy. Could that be made available to them? Your child's handwriting isn't very...they struggle to handwrite. Could I have an iPad, please? Or could I have access to a shared TA support? So you're shifting the focus away from behaviour onto what the needs are for the child. And think, when you're doing that, you're providing helpful solutions to the school so they don't have to deal with those problems. You're providing those solutions and in a respectful, positive relationship. You're more much more likely to get what your child needs. If you need advocacy to deal with school or you need support, please go to [SNAP Cymru](#), they have a helpline. Go to parent groups. There's always support there.

The Do's and Don'ts of advocacy. OK, so do identify your trusted adult. I can't say that enough and request they be your point of contact. Work to build positive relationships. Put information in an e-mail if you can and request a follow up meeting and e-mail. Outline the issue and suggest a solution. Take someone with you to meetings to take notes. That's quite an important one. You can ask for an agenda before a meeting and who will be in attendance and ask for a copy of the notes of meeting. If you're looking after a fostered child, NIAS will provide advocacy and support you, and also you can have support from the Children's Commissioner for Wales if the child is in education, they will support you up to the age of 25. Do not expect everyone in the school to know and understand your child. They don't. You know, you find that nugget of gold in the school and you build on that. You don't raise your voice or shout. Don't go there. It doesn't work. Don't overly chase a response. Think about - is it urgent? Don't telephone when you're upset or angry, because if you upset the staff, they're human as well and they may shy away from engaging with you and your whole focus is getting what your child needs. Do not go to meetings alone. Make sure you take someone - another pair of ears is really helpful and somebody to take notes as well. And when you do get those meetings which are really rare, when you think about the number of children that schools are dealing with, the problems don't waste time on what's gone wrong before you know, we can get sucked in to that, can't we? What make the most of the time that you have while you're in the meeting - what do you need now? Forget past issues. See each meeting and each conversation with school as a fresh start. Don't carry over those issues because it will show and reflect in your language when you're talking to your child at home. And remember, you don't want to be convincing them that it's not safe to be there.

I'm just going to touch quickly on the strength focused approaches because this is really important when we're thinking about the strengths of our children and young people. Neurodivergent children are known to have some great strength, such as creative minds - when they're interested in something, they hyper focus. So if you want to know any details about a subject and your divergent child is interested in it, ask them. Because if you want to know they'll know everything, right? They become experts very quickly. And they're really good at pattern seeking, linking ideas. Empathic, compassionate, social justice warriors. They're really good at spotting errors, different thinking, thinking about seeing patterns. Lateral thinkers. So really think about your child and their strengths and how can they bring that into the school

environment and how they can use that at home. So you can start making that their main identity and school can make that their main identity and lift that focus about what is wrong, let's shift the focus into what is right and when we want to look at strength focused approaches. We're thinking about creating aspirations. So Dr Halliwell in America talks about it like a Venn diagram - what your child is good at and what do they enjoy makes the aspiration. So, for example, my daughter is really compassionate and empathic person, really sensitive and strong sense of social justice, and she also loves animals. So we've told her she'd always make a great vet or a veterinary nurse, and so that's now what she is currently pursuing to go into college to do. If you have somebody who's a kinaesthetic learner but likes to cook, perhaps they want to be a chef, somebody who loves reading, and is interested in science in school, perhaps say to them "you'd make a great researcher or teacher." Create that identity, that focus, that aspiration, give them something to work towards. Because they are going to be OK, they are going to get there.

So how can those strengths be used in school? And have a chat with [Careers Wales](#) because what you can do is, once you've identified the aspiration and you've identified something that they want, they may disagree with you, you know, but you can give them a selection of careers. And once they say, "yeah, actually I fancy doing that," go to Careers Wales and work backwards and then you can identify the path, the subjects that they need to engage in in order to get to that goal. It gives them purpose in their education and it gives them hope. So looking for families for those children who are struggling. To have an assessment for those families who were experienced school avoidance, you can go to the [Do-It Profiler](#), which is Professor Amanda Kirby's website, and you can download a profiler. It's £25 from the age of 7 to 16. If you're unsure and there's something going on underneath - "I'm not sure what it is, school are not quite sure either." It's not diagnostic. But what it does, it identifies the needs and the strengths of your child. It basically provides you, if your child is neurodivergent, with a spiky profile and it'll tell you what that spiky profile is. And that profile will be what support needs to be put in and what you can do to harness those strengths. So please go and have a look at that profiler and you can share that objective assessment with the school ALENCo to produce a plan for support. Remember this is small steps - be child-led. What you want for your child may not be what the child wants, so meet the child where they are and build slowly. Sometimes children say "I don't want help in the classroom. I don't want that." OK, so don't have it at that time. Just build a regulated

connection with the child, build those relationships and empower the child by identifying what those social, emotional, and educational needs are so they can self-advocate. Build those trusted relationships, focus on their strengths and then you know over time, step by step, you should get the support from school where your child needs to be. And don't forget the importance of self-care. You know a lot of us are neurodivergent as parents ourselves. A lot of us are trying to keep it together and you carry a heavier load of having a family, working, dealing with a child who may have mental health issues or may not be in school. You need support too. You can't pour from an empty cup, so please make time for yourself regularly every day and every week to model self-care again. Model problem solving. Immerse yourself in your own special interests and passions, because that's good for you. And reach out. It's not weak to reach out and say if you need to, to the school, "I need help as well." Join a group. You can go on to the [Dewis](#) database and find third sector or statutory service support through the [Family Information Service](#), get involved, get involved with the child, meet them where they are arts and crafts, family walk, sports and exercise. Do some gaming with them. Spend some positive regulated time with your child and just be a bit more kind to yourself.