

# Sparkle - focus Group

15 September

## Committee attendees:

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- Jayne Bryant MS
- Naomi Stocks, Clerk (note taker).

## 1. Background

**1.** This visit was facilitated by Sparkle, the official charity of the Serennu Children's Centre in Newport, Nevill Hall Children's Centre in Abergavenny and Caerphilly Children's Centre. They support children and young people with disabilities and / or development difficulties and their families living in Gwent.

**2.** The session was held following a request from Sparkle to enable the Committee to speak directly with families for the Committee's inquiry "Do Disabled Children and Young People have equal access to education and childcare?" Sparkle advertised the session across their social media feeds.

**3.** This note provides a summary of issues discussed and raised.

**4.** We note that there will have been some people who would have wished to come and share their experiences but were unable to do so because they were looking after their children.

**5.** Over 25 people attended. The Chair of the Committee, Jayne Bryant MS, attended, alongside the Clerk, Naomi Stocks (who took the notes.) The Committee is very grateful to all those who came and shared their experiences.



**6.** We heard a broad range of experiences covering different ages, types of disabilities, level of support needs and educational and childcare experiences. The unifying theme was a clear passion to ensure that children and young people could access the full range of education and childcare opportunities. This was accompanied with frustration and anger about how the current systems do not deliver even on basic needs. A number spoke of how a child's right to an education was simply not being met. For those children who are able to access education or childcare, their experiences and opportunities are far more limited than those of their non-disabled or neurotypical peers.

**7.** We heard repeatedly that equality and inclusion does not exist. Many people compared the experiences of their disabled child, with their non-disabled children or peers, to highlight the stark differences in experiences. This inequity stretches beyond education and childcare, and is prevalent in all aspects of their life. Someone said that the issues raised during our discussions, were the same that were being raised twenty years ago. Another said it was reflective of how we treat disabled people more broadly in society, and they called for them to be treated as a child first and foremost, with their disability as a secondary factor.

**8.** We also heard of a lack of joined up working between different agencies and support services. People talked of differing criteria for support across different local authorities, schools or support organisations, and a confusing mix of different funding streams. They said that families are regularly passed from one organisation to another, and it is difficult to understand exactly who is responsible. Additionally, there were concerns about how far removed decision makers were from the child and their family, and that it is difficult to get the child's voice heard in these decision making structures.

## 2. Statutory school provision

**9.** Some felt that how welcoming, inclusive and accessible a school is, is more dependent on the characters of the staff rather than the systems underpinning the school system. People described how the system is setting children and young people to fail.

**10.** Concerns were raised about children and young people who "fell into a grey area". We heard of a number of children whose needs did not require a specialised setting, but were struggling within a mainstream setting. People talked of the "big gap" in criteria between mainstream and specialised support. We were told that education in a mainstream setting and that in a specialised setting are "totally different".

**11.** Parents called for a clear and consistent route to children and young people being able to access Education Other Than in School (EOTAS). They wanted more transparency about the range of options that might be available, highlighting that EOTAS can be appropriate for children who are in the “grey area”. One parent described how they had to use a FOI request to access the local authority’s EOTAS policy. They said decisions were still being made based on diagnosis rather than need and said a GP letter had not been considered sufficient.

**12.** One parent described their child as being “forced” into mainstream provision which is not meeting their needs. Another said their child needed to be a specialised setting but that this was not being listened to. One family member described how their primary school has “done brilliantly coping within the resources they have”, but that the children are now refusing to go. They’ve been advised that if they apply for a place in a specialised setting, they may get a place next September, and thereby they losing out on even more education.

**13.** Another parent described how their child has missed six years of primary school because the local authority has not provided an accessible school place. They described how the first placement, lasted only six weeks, because the child was not treated normally. In the second school, 12 points of disability discrimination were upheld. While they are now in secondary school, there are issues around transport, toilet access and lunchtime facilities, all of which are causing the young person to be segregated from their peers. The care plan and IDP are not been followed so opportunities such as blended learning are not happening.

**14.** One person described the EOTAS panel as the “real power broker” but that they have no information on who sits on it. The school, the family and the learner are not allowed to represent themselves at the panel, yet this panel makes all the decisions including transport provision and level of specialist support.

**15.** They went onto describe their child’s case, who had been diagnosed with autism, ADHD and dyspraxia. Their child had been a top student, but it all “fell apart” after the pandemic, and they’ve been unable to attend school. Their child then became physically disabled, and despite letters from around 30-40 consultant level professionals, the panel said there wasn’t evidence her needs weren’t being met. Yet the school said that they couldn’t push the wheelchair, so they would need 1:2:1 support just to get between classes. It got very challenging, and the school did not develop a plan to support their child. When they started putting things in writing to the school it “got turned on me” and social services got involved. They said they had a “year of hell, instead of fighting for my child, I had to fight to provide I was not hurting my child.” They said that they had a good social worker and that they were vindicated in the end, but that the

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process was much worse than dealing with the onset of the their child's serious physical disability.

**16.** We heard a number of families talking about the impact of emotionally based school avoidance, and a lack of appropriate support. One parent described how a number of schools had told them to "off-roll" but that this was all being done verbally, so that there was no paper trail. They felt that their child would benefit from "Nurture" provision, which would provide the required emotional and social support their child needed. However, there is no such provision for children and young people who do not display challenging behaviour. As a result their child has been out of school for two years. They noted that this absence has saved a lot of money for the school, and that the local authority is currently not meeting their legal requirement to provide schooling for their child.

**17.** We were told that children are being physically excluded from the school estate because of their disabilities. Parents described authorities not seeing a child but "something different? One parent asked why aren't we ensuring that they are fully included right from the outset of their lives? We also heard that the numbers of children and young people with disabilities are increasing.

**18.** Parents said that accessibility starts outside the school gate, which schools often forget. They talked of the challenges of being able to drop off their children, with a lack of safe parking places, or access to disabled spaces outside schools

**19.** We also heard about disabled children and young people not being able to access residential opportunities. We heard that children in Learning Resource Bases are not offered any residential trips. But even those in mainstream settings, may not be able to go. One parent described how their child was barred from going because there would not be sufficient support. They had offered to go themselves, but they could not get a DBS check completed in time. They felt it would have been a great opportunity for their child, and the fact they couldn't go was upsetting for the whole family. They called for a more person-centred approach, and suggested setting aside some money that can be accessed to enable disabled children and young people to access residential activities.

**20.** We heard about the lack of choice for disabled children and young people. It can be difficult to find a school that is inclusive and accessible, and therefore unlike non-disabled peers, these children often just have to go to the school that most closely meets their needs even if it's not the school they would particularly chose.

## **School funding**

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**21.** Issues of school funding and the impact limited budgets is having on school decisions were raised repeatedly. Families said a whole school approach was needed, and schools should be “fully funded” to deliver this. We heard that governors have limited options in managing budgets, and that deficit budgets cannot be set. Therefore with other costs increasing, one of the few options available is reducing teaching assistants (TAs). Yet, TAs “do wonderful work”, and provide support for children with ALN which a teacher who has responsibility for up to 30 other children cannot. This was also linked to changes with the ALN system, people described how statements had acted as a safety net because the money followed the child, but recent reforms mean this safety net has been lost.

**22.** One person described schools are “operating on a shoestring” financially. Another accepted that schools can only work within the budgets that they have. However, they also noted that while the local authority say schools should accept reasonable adjustments to support education, they do not actually provide them.

**23.** We heard that schools can often be reliant on support from charities and volunteers, especially those who may have specialised knowledge in supporting specific disabilities or conditions.

### **Staff training and capacity**

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**24.** Issues of training for school staff was raised. Specific issues highlighted included the need for SENCOs to have mandatory training, as well as TAs. It was suggested that specific training should be included in education related degrees and masters. This is important because teachers in mainstream settings will also be dealing with children with ALN. People described the “real impact” having staff with the right skills and experience has on their children. We were told that it was important that there were “trusted adults around them who understand their needs.”

**25.** One parent called for more training specifically for staff in learning resource units. They said that their eight year old who has a ADHD diagnosis has not had a “full on education”. Even in a Learning Resource Unit, their diagnosis is not taken into account and staff say that they are “naughty” when the behaviour is because of the child’s ADHD.

**26.** We heard that it was important for educational professionals to have training and time to explore their own unconscious biases including on disability. We were told that unless this happened, the culture in schools would not change.

**27.** Protected time for ALN support was raised. We heard of a number of examples where SENCO responsibilities were just done “on top of” the postholder’s teaching job. As a result a

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child with ALN couldn't access this support because SENCO was unavailable due to their teaching commitments. We were also told that some times teachers are not being paid for this additional responsibility.

### **ALN reforms**

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**28.** Funding for the current ALN reforms was raised. There was concerns about how long the ALN funding would be ringfenced. People were concerned, because previously the autism budget was ringfenced for a couple of years, but eventually the ringfence was removed.

**29.** One parent described having to threaten to go a tribunal to get a statement. Another said that their child was refused an IDP, which then had a direct impact on their child's mental health and wellbeing, resulting in an attempted suicide.

**30.** We heard comparisons between the previous and new systems. One parent described the experiences her elder child with ASD had, and that of her younger child who is on the new system. When the older child transitioned from a Learning Resource Base into mainstream provision, the funding followed seamlessly, enabling the child to dip back into the additional support from the LRB when needed. This helped support the transition to mainstream provision.

**31.** However, as their younger son is now also transitioning from a LRB into mainstream there has been a lot of discussion with the school about the funding sources. (This didn't happen with their elder child.) This is because the funding for those in the LRB who have an IDP, comes from the local authority, but the school itself will have to fund any further support their child needs. They said that their child needs to be in mainstream provision, the LRB is not meeting their needs, but they still need some additional help. The ALNCO has said that the school is scrapping the barrel in terms of budget.

**32.** In comparing the two new systems, they said that the paperwork is an improvement on the old system. They felt that the length of some of the key documents, such as a learner's statement, meant that teachers did not have time to go through them in detail. The statement often became very outdated, citing that when their child was 15, the statement still included details that related to when their child was diagnosed at two. The IDPs they felt were "largely positive, more concise and more about the child in the here and now."

### **Diagnosis, assessment and support**

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**33.** Numerous parents talked of having to access private healthcare in order to access diagnosis and assessment. This was primarily because of the length of NHS waiting lists. This was for a range of different conditions including ADHD, autism and dyslexia. It also ranged from

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medical diagnosis but also support from allied health professionals such as occupational therapists, psychologists, speech and language therapists. For many going private meant accessing a range of different professionals through this route, with the costs attached to seeking a range of different professional advice. Someone said they were now considering accessing private healthcare in order to secure a diagnosis, with this likely to cost around £6,000 in total.

**34.** Even in those instances where support is provided, there can be hidden and additional costs. For example, one family described how they had finally secured a funded communication device, only for it to break down regularly, and the high costs to repair it have to be paid by the family.

## **Tribunals**

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**35.** A number of families talked about their experiences with tribunals. We heard from a number of people the view that the money local authorities are spending on tribunals could be redirected and spent on providing support. It was highlighted that 70% of tribunals are successful.

**36.** A child's right to education was highlighted, yet, parents are having to fight to have this basic right met. Somebody said that the biggest issue they face in securing their child's education is the local authority. There was concern that local authority staff don't have sufficient training or awareness in disability.

**37.** One described having to provide all the reports in medical terms, despite there not being a person with a medical background on the panel. Another told us of having to go private for a diagnosis and the school and local authority not accepting it because it wasn't done through the NHS. Yet the NHS waiting lists were too long. As the local authority would not accept this diagnosis, they had to go to tribunal, which cost them £17k, and was successful. This was financed through remortgaging their house. They questioned why the local authority had not accepted the private diagnosis in the first instance, especially when it was the same Doctor who would have done the assessment in the NHS.

**38.** We heard of one particular case, where as a result of a family going through the legal route to secure appropriate accessible and inclusive education, they can now only communicate with their local authority and school through solicitors. This includes simple conversations such as letting the school know when their child has an appointment and will be late to school, or even other contact with the local authority such as requesting a new food caddy for recycling. The expense of this for the local authority was highlighted.

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## Exclusions

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**39.** We heard of examples of children being excluded because of their disabilities. One family cited an example of being called in by the headteacher and told that the school didn't want "this type of child" in their school. Their child has autism.

## Learner Transport

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**40.** Issues around accessible learner transport were raised. People said that the learner travel provision needs to be more clearly spelled out, so that it's clear what people can access.

**41.** As well as hearing about issues around pre-16 transport, we heard about post-16 provision. People described there being "no clear direction". Difficulties arise in making post-16 choices because the transport offer is not known. Some described finding out what transport would be available only the week before the new term or "even the day before."

**42.** One parent described having to pay £178 a week for an accessible taxi for their child to go to college. They highlighted that if they were living in a different local authority they would have fully funded transport. When they raised this, they were told that their child "shouldn't be enrolled in college when I knew I had no transport." As a result they have had to change their working patterns so that they can take their child to college, with an accessible taxi picking their child up. This is still costing £88 a week. The inconsistencies across local authorities is "spurring" the parent on to continue fighting for their child.

**43.** The young person said simply "it's discrimination – I can't get on a bus...how am I suppose to get to college without transport?" They highlighted that non-disabled young people can access subsidies to reduce the cost of transport, and asked why this wasn't also available to disabled young people.

## Post-16 provision

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**44.** While post-16 provision is outside of the scope of the inquiry it was raised as an area of concern by families. We were told that support in a school setting stops at 16, meaning some children can't go onto sixth form provision. This was described simply as "discrimination".

**45.** There was concern about the length of funding available for support, an example was given where a young person "over performed" and therefore was not able to get funding past the initial two years. The family said that if their child had failed the funding would have continued. They said that while the Welsh Government have said that there's nothing in the



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relevant framework that this funding is only available for two years, the small print means it's actually very difficult to get additional funding.

### 3. Childcare provision

#### Pre-school provision

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**46.** There is not enough pre-school provision available to disabled children. Families described nurseries not taking on their children because they could not get sufficient funding for the additional support that would be needed. A particular challenge is the need for more staff.

**47.** One parent described having to pay for private childcare provision to help her child socialise with other children, yet this funded provision was available for non-disabled children.

**48.** Another parent described securing a place at nursery for their physically disabled child. However, following promising discussions with the nursery, and a settling-in period, they were informed the day before the provision was due to start that the nursery couldn't support the child. There was no opportunity to discuss this further with the nursery, so they had to find another childcare provider at very short notice. Despite the challenges of pursuing a complaint both in terms of the time, but also the "headspace" they did so. They got no response from the nursery directly. They contacted Care Inspectorate Wales but found their response insufficient. CIW's position was that the nursery had been apologetic and just hadn't realised the extent of the child's needs. The parent was frustrated that no alternative was provided. Despite subsequently securing a placement, whenever the setting had staffing issues, their child could not go in, impacting on the parent's ability to work.

**49.** The parent said "accountability was key" and suggested this could be improved by making more data publicly available to show when children and young people leave nursery or school places. This data should include information as to why children and young people are leaving their nursery or school. It was suggested that movement between settings both in the pre-school and school sectors because of a lack of support "happens all the time...it is not recognised and it goes under the radar."

**50.** One parent described how they had to take a career break when their baby was born during the pandemic. Due to the nature of their job, and because their child was clinically vulnerable they couldn't return. This was a job that they loved. When they have since tried to find childcare it has been difficult. During settling in sessions, their child was being placed with babies, despite being a pre-schooler. While their child is physically delayed, she is cognitively the correct age. Nurseries told them that it was not financially viable to take their child.

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**51.** They have since received support from Early Years Wales, who have been “great”. EYW assessed what the level of need was, and provided their child with the opportunity to attend nursery. The family wanted to increase the hours, but EYW wouldn’t fund additional sessions, and the family were not allowed to pay for additional sessions. They are now unable to find wrap around care for the school nursery provision. In their case, they are able to fund further provision, but they are being prevented because “it’s not allowed”. They said “accessibility, quality....nothing tangible comes out of these words.”

**52.** They said it was incredibly difficult to get a clear understanding of what support they were entitled to, and how to access it. They wanted a clear pathway which shows who is responsible for what, and who is accountable for ensuring this provided. They highlighted that the school is trying to be as inclusive as possible, but that there are limited funds available.

**53.** There are also issues around timeframes and deliverables not aligning. For example, they accessed an educational psychologist who could then feed into the IDP. However, the assessment cannot take place until the June before the academic year starts in September, which is close to the transition period. It meant the school had 45 days to create an IDP, and the “clock stops at the summer holidays.” They said if they hadn’t been working with the school for the previous year, their child would not have been able to start until October. While acknowledging that children’s development does change rapidly, they felt this alignment needed to be looked at.

**54.** The importance of early diagnosis and intervention was highlighted. People also highlighted that the need to secure appropriate childcare is often at the same point that families are discovering that their child is disabled. One parent described how their experiences fighting for childcare then affected how they approached securing a school placement. They were “terrified” and “shaking” when looking around schools because of their difficult experiences with childcare. (see paragraph 48.)

**55.** Ensuring support is put in place as early as possible was emphasised, because if not or if it is lost, the child never gets that chance again with their education. We heard of delays to diagnosis, including a wait of seven years to get a ASD diagnosis for one child, and three years for another child.

**56.** Issues with the catchment areas for Flying Start were raised. One parent believed that if they had access to Flying Start provision, their child would have been diagnosed earlier. (The postcode based access to Flying Start was also highlighted, with people describing how Flying Start provision can stop midway along a road.) People said what might make sense on a map “doesn’t make sense” in real life.

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## Wrap around and holiday provision

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**57.** We were told of a lack of appropriate wrap-around and holiday club provision for disabled children and young people. We heard of how children are being turned away from breakfast and after school clubs because of their disabilities or additional learning needs. The impact on parents and their ability to work, or care for their other family members was highlighted. One parent said they can only work term time, while others talked about having to stop working altogether. One person described that because of the children's needs they are "prisoners" at home because they cannot leave the house.

**58.** The recent report by Contact looking at [holiday club provision for disabled children](#) was highlighted. It calls on UK Government and local authorities to ensure that at least 15% of activities funded through government holiday and food schemes to be specifically for disabled youngsters. Parents also called for a percentage of all funding for play, sports and culture to be targeted at disabled children and young people. They also wanted to see penalties if this did not happen.

**59.** We heard that one of the barriers to holiday provision can be the fact that more staff are needed to provide the right level of support, and that such temporary posts are not easy to recruit to.

**60.** We heard that families are reliant on services provided by the third sector, and centres like Sparkle. Concerns were raised about the level of funding that these groups have, while there was a clear call for expansion of provision. Families called for disabled children and young people to be "more included" in provision. They also called for more local authority provision.

**61.** The adequacy of provision when available was raised, with one person highlighting that just because something is badged as "inclusive" that doesn't mean it actually is.

## 4. Impacts of unequal provision

**62.** A very clear theme amongst everyone who spoke was that they were constantly fighting to get their children and young people the support they need. One parent said that they have had to "fight, fight, fight all the time" and was now "losing the will to fight" in their latest battle to secure funding for learner travel.

**63.** The emotional toil this takes was clear. One person said they knew of several people who have attempted suicide because of stress and anxiety. Others described having to go onto antidepressants. They also said that this emotional stress was then having an impact on their

children. One young person said at the end of the session that until today they hadn't realised the impact that challenges of securing their education was having on their parent.

**64.** We heard of instances where families have been reported to social services (see also paragraph 15). One said that they were reported because their child had been violent in school, which was the direct result of the child's additional learning needs. They said that schools are not meeting their children's educational or social needs. Families are often having to deal with the same challenging behaviour that schools don't know how to deal with. This then has a significant impact on the whole family. They felt that when social services are blaming parents, the fault lies at the education system.

**65.** We heard terms such as "gaslighting", while others said that "parent blame is a big thing". People said these referrals to social services are "so harmful. One described of a head teacher accusing a family of harassment and that they were then referred to the police.

**66.** We heard repeatedly of the wider impact unequal access can have on a family, many have had to either reduce their working hours, change jobs, or stop working altogether. One parent described the importance of working not just to increase the household income but also for their own mental wellbeing.