

# Do disabled children and young people have equal access to education and children – discussion group

15 September

## 1. Background

- 1.** This session followed a discussion with parents as part of the Committee's visit to Ysgol Bryn Derw in July 2023. Members of the Committee were invited to discuss issues around childcare in more detail with parents, including with those who had experience of setting up childcare provision.
- 2.** We note that more parents may have wanted to attend but could not because of childcare responsibilities. We also acknowledge that there will be others who may wish to contribute to our Committee's work in other ways but will not be able to either because of a lack of time, or because of the
- 3.** 6 people attended. The Chair of the Committee, Jayne Bryant MS, attended with the Committee Clerk, Naomi Stocks (notetaker.) The Committee is very grateful to all those who came and shared their experiences. Everyone spoke with great passion about their children, and their experiences.



## 2. Oakhill ASD Childcare

**4.** Oakhill ASD Childcare is Newport's only ASD specific school holiday childcare provision. It was established after the school asked the governors if they wanted to set up childcare provision. Initially, it was wrap around provision, but parents said that holiday care was the more significant issue. This was because school transport is not available for wrap-around provision, and maintaining routines is more challenging in the holidays.

**5.** Oak Hill ASD Childcare was established in 2020, with the pilot scheme running in October 2020. This went really well, and was particularly needed because of the pandemic restrictions meaning children had been at home a lot. This was then followed with more provision in February 2021 half term. It then ran in summer 2021. However, it was a "constant treadmill" to fund and run the service. It was clear it was not sustainable to run it purely on a voluntary basis, so they decided to focus on summer holiday provision as this was the most needed. It was then run for the summer 2022 holidays, but as a manager could not be recruited, one of the trustees (who had the right skills and experience) stepped in.

**6.** Following the Summer 2022 provision, it was agreed that an all-year manager was needed because it too difficult to recruit someone just for the summer holidays. The Manager could then also be undertaking assessments throughout the year, and would understand what support the provision needed to provide. (Previously assessments had been done by a different person.) It is important for the scheme manager to assess the child at school and at home to ensure the provision can meet their needs. It is important that assumptions are not made about a child's individual needs.

**7.** Even with a full time post, it has been difficult to recruit because of CIW requirements for such a post holder. They must have playworker qualifications, have experience of managing a childcare setting and have an understanding of ALN.

**8.** The challenges around recruiting staff was highlighted, partly because it's transient work, so there are only certain types of people applying. This combined with the requirements to have a playwork qualification makes it challenging. Also because of the transient nature of the work, they cannot provide apprenticeships or access free courses to get potential staff the qualifications. Staff are often students, who often have personal experiences or contact with autism. However, some staff can surprised at the level of support needs, for example having to change a teenager's nappy.

- 9.** CIW has provided an exemption to waive the requirement for all staff to have a playworker qualification. Without this written exemption they would have been able to open in Summer 2022. However, the Manager and Deputy Manager must hold this qualification.
- 10.** They are licensed for up to 16 children and young people. Most of the children come from Ysgol Bryn Dewr, and have complex needs. In the first year, they averaged between 6 and 8 children and young people per session. They did not run at capacity because they could not recruit enough support workers, and because of the pandemic. In 2021, 10 children and young people attended. They were able to recruit students from Cardiff University, but then they did not have enough physical space for more children and young people. The school has subsequently provided more space.
- 11.** Whilst most childcare settings run up to 11, Oakhill provides spaces for children and young people between the ages of 3 and 19. This wider range of ages provides additional challenges. Teenagers are not just physically different to the younger children, but they have different interests. For example, older children may want to play with Lego, but this may present a choking hazard to younger children. However, having more space will enable Oakhill to increase capacity
- 12.** The provision has been very successful and has a waiting list. Asides from the recruitment issues, there are also funding challenges. It costs between £40-50k for the summer holiday provision. All the funding comes from grants. For example they have received money from the Children and Communities Grant, but this is a small fund to cover the whole of Newport, and much of it is taken up with children in mainstream settings. They also have received National Lottery Funding for the full time Manager post.
- 13.** While parents pay as they would in a mainstream setting, the fees don't cover the costs of 1:2:1, 2:2:1 or even 3:2:1 support. The ethos is always about providing high quality and safe care. Social Services has allowed some parents to use their direct payments to cover the costs, but this is not widely advertised. Direct payments in themselves are a stressful and difficult thing for parents / carers to administer and use.

### 3. Experiences of families

#### Childcare

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- 14.** We heard of the challenges over the 2023 summer because Oak Hill had not run. One parent described being offered four, three hour sessions over the whole of the summer. Dates for this childcare was only offered on 17 July. When questioning the dates offered they were told
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“tough luck, it’s not respite, it’s play, it’s not childcare.” They compared this with the choices and availability for a non-disabled child. They said saying disabled children and young people just “get no choice.” People said they can’t choose where they go for childcare and can only take what limited provision is offered.

**15.** One parent said that the school holidays were too long for children in specialised settings, and called for the length of holidays to be looked at for this cohort of children and young people. They said their needs were very different to those in mainstream settings, and there should therefore be differentiated holidays.

**16.** Parents called for more flexible holiday provision, including it going beyond the age of 12. One parent described their child who could go to mainstream provision but “won’t be given the chance...”

**17.** Childcare is also important to ensure that parents and carers have time to spend with their other children and family.

**18.** People called for a closer link between education and childcare, while saying creating these closer links doesn’t mean that childcare needs to become education. We heard that schools want to keep a clear distinct line between school and childcare. It was highlighted that childcare provision is more strictly regulated than school provision, citing that a teaching assistant can be employed in a school setting without any qualifications, yet a similar post in childcare must have certain qualifications. We heard of the need for a more blended approach between education and childcare.

**19.** It was suggested that empty school buildings could provide an opportunity to offer provision in spaces that would be familiar to children and young people. Even if they weren’t available for childcare, it would be helpful if these spaces were accessible to families during the summer period.

**20.** One of the trustees at Oak Hill said however that rent still has to be paid to school. There is still significant cost, which is why they run as a charity, as it wouldn’t be financially viable as a business. They would like to run provision for the whole of the summer holiday, but it’s not practical.

**21.** People raised concerns that training and qualifications, such as the playwork qualification, does not cover how children with ALN play, which is often quite different to their peers without ALN. They suggested the need for a complex needs play course, that would cover different ways to play, triggers, and de-escalation. They also flagged the differences between a

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teaching assistant role in a mainstream setting compared to one in a specialised setting saying it was a “different world”. They called for training that suits the setting.

**22.** One of the parent / trustees for Oak Hill said it shouldn’t be the responsibility of a charity, and volunteers to run such provision. They said that the provision is great, but “we can’t take it to the next level...” . They said it’s particularly disheartening that the children they cannot take at Oak Hill are already children who have been turned away from mainstream settings. They asked where do they go, if even specialist settings can’t accept them?

**23.** They talked about how these children are simply not seen, but as a parent they often “push ourselves to go out” to make sure that their children are seen. Other parents talked about how they will have to think carefully about where then can go to public places such as parks with their children, often having to go very early in the morning. They described being a “hidden part of society.”

**24.** Other suggestions that could help improve availability of childcare included enabling teaching assistants to be employed in the summer to work in childcare provision. It was flagged that teaching assistants are not paid over the summer holidays, so this could be a helpful additional income.

**25.** There was also discussion about the expectations that are being placed on staff. It was highlighted that such jobs are often minimum wage or living wage, yet have to provide a high level of care. They said while people are aware of these issues for older people’s care, the same issues are prevalent for children and young people and are less well known.

**26.** One parent described the approach taken in Australia, where parents pay for their childcare provision, but there is a sliding scale of subsidy depending on how much you earn. They also indicated that SEN children in Australia get 1:2:1 support.

## **School provision**

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**27.** Despite the challenges in securing a diagnosis the number of children being diagnosed has increased, yet at the same time, mainstream settings increasingly will not take these children on.

**28.** People raised safeguarding concerns about the lack of contact when their child stays at home. They said if their child does not go to school, no one checks on them, or provides support while they are away from school. One person said “the school was sucking the funding for him, but no one got in touch.”

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**29.** We were told that provision within special schools need to takes account of individual children’s needs. One parent said introducing Welsh can be challenging for children who already have language difficulties.

**30.** One parent said it was important to acknowledging that parenting and educating children with these types of disabilities and conditions is different, and that changes are needed to ensure these differences are reflected in the education system and the wider support.

### **Support from statutory services**

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**31.** Parents shared their wider experiences. We were told that families often don’t know what support they are entitled to, and don’t know what they can ask for. They said that the advice and paperwork you receive does not set out clear information about the support that can be accessed. Not all families have a social worker, and it can be difficult to get such support. People described “families falling apart” because of a lack of support, and that it was the “luck of the draw” in terms of who gets support. Even those who do get support from social services can find that the support patchy and variable. One person described a social worker saying they were “disabling their child by claiming” social work support was needed. We were told that “no-one is doing anything” and that families “can’t win.”

**32.** People described “mysterious criteria” with no clear rationale for the decisions that are made. We heard that it was unclear how decisions could be made when there had not been full assessments undertaken, or detailed discussions with the child / young person and their family.

**33.** They described the challenges in accessing support such as over-night respite. One person described knowing a family that bought a caravan so that the parents could have somewhere to sleep, and in particular to ensure that the parents could maintain employment.

**34.** We were told that the amount of paperwork that has to be completed is exhausting and draining. The nature of the forms, often mean families have to talk about their children in very negative terms. We heard that a reduction in the levels of bureaucracy would help free up families to spend more time supporting their child. They called for improved streamlining and better coordination between different services. Processes need to be simplified, and families should not have to beg for the basics that non-disabled children and young people get automatically. We also heard that local authorities need to more open to feedback.

### **Impacts on the wider family**

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**35.** There was a very strong theme around the impacts on the household finances, as well as the wider emotional and wellbeing impacts from parents and carers being unable to work.

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People described being told that they had to stop working to look after their child, yet the system does not help support families financially to do this. One parent described how the need to work part time was not understood or supported by the DWP.

**36.** One parent described how they had to leave their career when their child was born and has not been able to work since. As well as losing their career, they have also lost their future pension. Their husband had also lost their job. They said “childcare, what’s that?” explaining that when they had tried to find childcare, childminders would be willing to help but could not afford to take their child on because they needed dedicated 1:2:1 support. We were told that once your child has received a complex diagnosis “everything is striped back”. Another parent also described having to give up their work and career.

**37.** Parents told of us of the financial and wider emotional impacts on their families because of a lack of support. We were told that four out of five parents of disabled children divorce, and that this then has a negative mental impact on children. Stopping work also has a broader impact on a parent and the family, particularly in terms of mental wellbeing. One parent said “I like my job, it gives me a break.” Another parent said that as a result of having to stop working, they now have no pension, meaning the state will have to support them for longer. They said it’s much better to have accessible childcare and support so parents can go back to work, and it saves the state money in the longer term.

**38.** They said that there is an emphasis from the Welsh Government to reduce poverty, and child poverty. However, they said that poverty goes beyond financial poverty, but also poverty of the quality of life. They said many families just don’t have any quality of life. Families struggle particularly with the long school holidays. If they are working, they can’t take six weeks off work, and the children and young people struggle with a lack of routine and continuity. It is exactly this need that Oak Hill was established to fill.

**39.** Parents described the “very different experience” of having a child with ALN. They said “you don’t get tea breaks, there is no respite.” They described how they have to provide support 24 hours a day. One parent said “it’s like having a baby, but they are very large!”

**40.** We heard of examples where children in school are receiving 2:2:1 or 3:2:1 support, but the families are expected to provide this support at home on their own. This can be particularly challenging in single parent households. They said if it is acknowledged more support is needed in the school setting, why doesn’t this translate into more support at home. We were told that “families are being broken...”

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**41.** Although outside the scope of the inquiry, issues around post-16 choices were raised. We heard that there was nothing local for one young person, and that it is likely they will have to go away.

## **Other issues**

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**42.** There was a clear frustration that no-one outside of the families cared about their children, or what happened to them. We heard that these are children and young people whose voices are not heard. Even in those instances when children and young people do make their views heard, this is not acted upon. One parent told us of a very concerning situation where their child was trying to demonstrate through their behaviour their distrust of a professional, but because they could not verbalise this, it was not taken seriously.

**43.** They talked about misconceptions of how an autistic child or young person will behave, or present. This can be both with professionals and also the wider public.

**44.** We also heard wider issues around the lack of support for these children. One person described issues getting suitable medical support for their child, which they said would not have been so difficult if their child had been neurotypical. They had to threaten to submit a complaint in order to get appropriate support.

**45.** We also heard about a lack of accessible and inclusive play areas. Parents talked about how soft play centres, trampolines, outdoor parks are often the places that their children when asked want to go to. But the accessible sessions for these places, if they are run, are often too early or late in the day. As they become older, these options become more narrow as these facilities are not suitable. Even spaces such as Sparkle don't meet older children's needs.

**46.** In closing, one parent put it powerfully, "I did everything society wanted me to do, and everything was taken away. It's not [their] fault, [they are] the apple of my eye. Everyone else is trying to screw us over."