

Stakeholder Event

27 September 2023

Committee attendees:

- Jayne Bryant MS (Chair)
- Heledd Fychan MS
- Buffy Williams MS
- Naomi Stocks, Clerk (note taker).

1. Background

1. On 27 September 2023 the Committee held a stakeholder event to inform it's inquiry: Do disabled children and young people have equal access to education and childcare? Stakeholders from groups which support children, young people and their families were represented.
2. This note provides a summary of the issues discussed. Some of the stakeholders involved had personal experiences as well as professional experience of these issues.

2. General issues

3. There was an ongoing theme of the need for families to have to fight for all support. We heard examples of families who have "fought the hardest" and yet provision was either not provided or was not maintained. We heard of a case where support was identified, but was then not delivered. We were told that the situation was "misrepresented" to the family, who had put trust in the people providing the support.



4. While another described despite navigating the system “from a place of privilege, they then found out during a tribunal that their child had not seen an occupational therapist for 18 months, despite plans stating they would see them weekly. There were concerns that even when a framework of support is agreed, there is no guarantee it will be delivered, and if it isn’t, families are not told. We were asked “why do people have to fight?” We were told that if a family has been appropriately assessed and the right provision is in place, there should be no battle. The reason that families have to fight is because the system is not “fit for purpose.” The impacts of the pressures of fighting on the whole family was highlighted

5. Concerns were raised for those children and young people whose families will accept whatever support is given to them because they “can’t, won’t, or don’t know how to fight”. People called for a programme of maintained support for children regardless of the ability of the family to fight for the support. For some parents / carers the ability to battle for all support may be impacted by their own additional needs. It was highlighted that some conditions will be genetic.

6. We heard that there are inconsistencies of support across Wales, and sometimes even within the same area or region. Families can be unaware of “life changing” support that they are entitled to or that is available.

7. People highlighted the changes over the past 30 years in the type of need. Thirty years ago it was primarily physical disabilities. It was suggested that there has been a failure to deal with both the increase and the change in need. As a result services are not managed in a way that addresses these changing needs. We were also told that there was an increase in families needing support.

8. It was suggested that improvements in identifying and addressing needs has partly driven these changes and increases. We were told that diagnostic assessments didn’t start until the 1980s and they were mainly focused at learning disabilities. However, the improved understanding of neurodiversity has led to better identification. We were told that these learners have always been in schools with these needs but they would have just “struggled in school.....previously seen as difficult and awkward.” Although, this was not the view of all participants. In particular, issues around diagnosis for girls were highlighted.

9. While outside of the remit of the inquiry, challenges around direct payments was also highlighted. Direct payments are issued in “lieu of services”. However, there are issues as local authorities have fixed rates for services, so if they don’t buy a service at the market rate, it can’t be accessed by those using direct payments.

- 10.** The importance of leisure as part of education was highlighted. We heard examples of inclusive leisure provision such as swimming lessons, play clubs and tech clubs being provided by the third sector. Questions were asked why this provision wasn't being provided by local authorities. We were told that inclusive provision is not being provided in mainstream settings, and as a result children and young people are being deprived of leisure opportunities. It was described as "blatant discrimination". We were told that families and their children want to go to integrated provision but that staff in these settings are not trained to support children with additional needs. There are also issues in mainstream settings of physical access, such as wheelchair accessibility.
- 11.** The challenges of provided integrated provision was also highlighted, and that integrated settings are not appropriate for some children and young people.
- 12.** Some of the inclusive provision allows parents / carers to drop off which can make a big difference to the parents / carers. Yep some, parents / carers have to stay for the duration. It therefore does not provide any respite or time for parents / carers to do other things.
- 13.** We heard that while wider society has improved in many ways, for example, businesses such as hairdressers will often run quiet hours that this wider change has not been seen in leisure / after school provision for children and young people. We also heard of the need for community spaces where families can go, and not worry about their children's behaviour. We were told that these spaces can be the "difference between make and break" as a family. It helps them not feel segregated.
- 14.** The importance of allowing children with additional needs to take part in activities such as residential trips was also highlighted. We were told "education doesn't just happen in the classroom."
- 15.** People felt strongly that these issues also speak to the wider issue of the place of children and young people with additional needs in society. There should be leisure facilities that they can access everywhere in Wales, and some of this is about upskilling mainstream provision. There is a lot of work trying to push cultural change and help settings become more inclusive. We were also told that the impulse to segregate at an early year can mean "out of sight out of mind" which has consequences into adulthood. There is a need for spaces for all children and young people to be together, to help build social cohesion longer term.
- 16.** The burden that is placed upon the family to find appropriate spaces was raised. It adds to the workload and administrative burden which is already very high for families.
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17. We also heard of the positive impact that Family Liaison Officers can have, and one third sector organisation described them as “one of the most valuable things we do.” One of their roles is to disseminate information to families on a regular basis, which was described as “really important.”

18. Across the piece, we were told there are examples of good practice, and people are trying hard to provide inclusive services. However, we were reminded that “disabled” children and young people are “not one homogenous group”. For example with neurodiversity we are only just starting to understand that reasonable adjustments should be put in place. Currently a lot of these children are excluded, and it’s seen as a behavioural issues.

3. Childcare provision

19. We heard of the challenges in securing accessible and inclusive childcare, and the impacts this has on parents and carers’ ability to work. We were told that when childcare is available it needs to be reliable to support employment . It was highlighted that playschemes are often not set up for that type of reliable and sustainable need. We were told that “lots of parents have had to give up work because of a lack of childcare”, and that there was a “huge pool of talent that was been wasted.”

20. Other challenges in accessing childcare, included a lack of provision for older children, as most mainstream provision stops at 11, whereas some disabled children and young people may need it up to the age of 19. We were also told that for some children and young people “generic access to childcare” will not be suitable, and that for these children and young people is a need for specialised provision that can properly support these children and young people.

21. We also heard about the lack of “short break” provision, which also has a huge impact on the wider family. Some did not like the use of the term “respite” because it frames the provision negatively, and said that using short breaks is more positive. This is because it has positive benefits both for the child (who spends time with people outside the immediate family) and the family. We were also told not to “conflate short breaks with childcare” because childcare is for working parents, while short breaks is a different type of provision. Short break provision has a “massive impact” on the whole family, including siblings, who are often also young carers.

4. Statutory school provision

22. We heard that there has been work with Estyn to ensure that inspections consider the needs of children with additional needs. We heard that it can be down to the individual

inspector. While Estyn have to look at wellbeing, we were told that feedback is not taken from families on their experiences. It was suggested that children with additional learning needs, who may not have received adequate support, may not have the opportunity to share their experiences with Estyn.

23. Some people asked whether Estyn are looking at the progress being made by these groups of children. This needs to take account of the fact that children and young people progress at their own pace. We were told it isn't good enough to rely on someone making a prediction about what they are going to, and were asked how do you identify if they are making an adequate progress. Concerns were also raised about the lack of aspirations for these children, and we were told that "school is not a holding pen."

24. The importance of an individualised approach was emphasised. We were told of particular approaches that may be used for children with additional needs but that didn't work for some children. The support needs to be person focused, and centred on the individual's specific attributes and needs.

25. We heard that there is a appetite from education and healthcare staff to do training required as part of the Code of Practice on the Delivery of Autism Services. We were told there is a clear need for this training.

26. In relation to Individual Development Plans, we were told that IDPs are not always shared with all the teaching assistants, yet these are the staff who often have to provide the support and manage any issues. We were told that teaching assistants often do not have the right training to deal with these issues, and that puts the teaching assistants under pressure.

27. Concerns were raised around attendance management policies. For example rewards for certain levels of attendance. For some children with disabilities, maintaining attendance rates of around 95% is "impossible". There were also concerns raised about anxiety based school avoidance, and the fact this is not recorded as a reason for absence.

28. We were told that there was a "big gap" in support around transitions between primary and secondary; and then into post 16 education. Although we also heard some positive feedback on support in further education colleges (which is outside the scope of this inquiry.)

29. We were told that there may be limited opportunities for children with additional needs to secure work experience, and is often not focused on what the young person is interested in.

30. We heard concerns about Welsh medium provision and support. This is more of an issue in non-traditional Welsh speaking areas. It was also highlighted that the level of Welsh medium

need was under-identified. The importance of assessments being done in a child's first language was also emphasised, especially around speech and language assessments.

31. There was also discussions around the increase of home education. This can be a positive choice for many. Some children and young people did not want to return to school following the pandemic, and parents / carers "don't want to push it." We were told there is a lot of anxiety around school attendance, schools can be very busy places, and school estates, especially new buildings, are often open plan, which are not very autism friendly. It was said that for some "school is just not the right setting." Other families are home schooling because they are not receiving the right support in school.

32. We were told that local authorities are "not forthcoming" on education other than school ("EOTAS"), which would often be of benefit to a lot of children and young people with additional needs.

33. Linked to these issues, there was also discussions about absences and exclusions for children with additional needs. We were told that absence and exclusion rates are "disproportionate" for these groups. For those children and young people on part-time timetables, there can be issues with recording attendance.

34. We were also told there are issues around "unlawful exclusions" where children and young people are just being pulled out of school. We were told that some parents are unaware of the requirements around exclusions, and that often schools will exclude informally, so they do not have to adhere to requirements for fixed term exclusions, where a return date must be set out in writing, and where the reasons for exclusion must be recorded. One parent described their experience, where they were "constantly" having to go into school to pick up for informal exclusions, where they would just be told to come back in a week.

School trips

35. We were told there was mixed practice around school trips, with some "really good practice in some communities, others not." For example, some schools will be able to support trips to Llangrannog, and others won't. We were asked if some schools can accommodate this, why can't others? We were told it was often down to a lack of planning, and not putting in place appropriate risk assessments. It was described as a "postcode lottery".

36. One parent said when they asked their child's school why they had never been able to go on a visit, they responded "we don't know."

37. Other barriers to children and young people being able to access school trips were given as financial, or the need to manage other children with other needs.

Learner transport

38. There were concerns about the accessibility of learner transport. We were told of cases where parents / carers have to accompany their child on learner travel because of concerns of the child's behaviour or concerns around management of a child's specific condition. Transport firms, in particular taxi firms, are concerned about the risks. It was felt there was a lack of planning and of risk assessments. Transport escorts need to be properly trained, and "most are not trained."

39. We were also told that often families are not offered transport initially, as there is an expectation that the parents / carers will be around to provide transport. It was cited as just one of the many fights "alongside the others." There can be challenges for families to provide transport, as it may clash with getting other children to different schools. It was described as "a massive problem." When these issues have been raised, the response from local authorities are for families "to sort it out yourself."

40. People said if you are able to work from home that may provide more flexibility to accommodate transport needs within the family, but not everybody is able to do this. Many families are reliant on having family / friends around to help. It was described as a "brittle service", and all it takes is for one piece of the jigsaw to be lost, for it to all fall down.

Tribunals

41. Concerns were raised about the number of families having to go to tribunals, and the level of stress and anxiety this places on families. One parent described the first tribunal they were involved in as "the most stressful thing I've ever done in my life." It was suggested, that there was a "perverse incentive" to local authorities to push people to tribunals as it delays having to provide services.

42. We were told that the system can drive you in the wrong direction, citing an example where a family was driven to get a diagnosis, despite the child not wanting this, as it was the only way to access support. In this instance, it was the solicitor who was pushing for a diagnosis. We were told that the system is "wrong", as the system should be listening to the child, rather than relying on diagnosis. People said that there was a lot about listening to parents, but quite often not listening to the child. The child has no say or no choice. In the case outlined, if the

system had worked around the needs of the child, they wouldn't have gone down the route that was followed.

43. Following on from this, people raised that often it is just the challenges of the child's behaviour that is highlighted and not their attributes. Simply, a lot of the time, children and young people are not asked what they want.

ALN reforms

44. We heard views comparing the new ALN system with the older system. One person who had experience of tribunals under both regimes, said they didn't think the previous system was outdated, although they acknowledged that others thought it was. They said the issues with the previous system was the implementation. These issues will continue with the new system, there is no guarantee that it will be effectively implemented. They felt the key issue is how families are engaged within the system.

45. Another highlighted that one of the key difference between the systems is that the new system should be needs led rather than diagnosis led. Although they did not feel this change has actually happened yet, with families often being asked for a diagnosis before support can be provided. They raised the ongoing concerns about the waiting times for diagnosis, with some children and young people still waiting years for a diagnosis.

46. We were told that some parents are not aware of the new system, or what an IDP is.

5. What improvements can be made?

47. We asked what changes would improve things for children, young people and their families. We had a range of responses.

48. Issues around scheduling appointments was raised. People asked why appointments aren't available over weekends / evenings? It was said that having a medical appointment on a weekend would be "one less thing to worry about." People said organising services around the needs of families as opposed to the needs of professionals "would be a good start". This is a particular issue for those who have multiple appointments.

49. The challenges of parents / carers having to be available at all times was also raised. The comparison was made between the employment rights people have as adults, where you can take time off for appointments, but the lack of similar rights for children or parents / carers with children with additional needs.

- 50.** This assumption of parental / carer availability goes wider, we were told. So it's also being available to do any therapy / work between appointments. One parent said they were asked "why are you working? Why not doing therapy?". They felt that changing this assumption would be helpful.
- 51.** There were suggestions to change the way people receive information about what support is available. We heard that there are frustrations around signposting services, particularly when the information is not up to date. It was felt this was an area where improvements were needed.
- 52.** Having more awareness, and improving wider knowledge about different conditions, and in particular around neurodiversity. This has a positive impact on everybody, staff and students. There was also a call for a "massive input into training for all staff, SENCOs and governors." We were told there are "massive gaps" in knowledge and understanding of conditions.
- 53.** Someone highlighted that there is a lot of free and accessible training materials on some conditions such as autism, and they were unclear why more schools didn't take up these training opportunities.
- 54.** The importance of the social model of disability was raised. We were told the Code of Practice on the Delivery of Autism Services does take a social model. Although it was highlighted that for some conditions, a medical model is also important, and there were concerns that not all the health services are available for children and young people with complex needs.
- 55.** We were also told on the impact on non-disabled siblings within these issues. They were described as "always invisible in these conversations."
- 56.** The importance of the DECLO role in coordinating between education and healthcare was raised. People asked how seriously HBs take the DECLO role, and to what extent has it improved the interface between health and education? Calls were made to understand the outcomes of the DECLO role, has it done what it should?
- 57.** We were told there was a need for a different therapy model. People felt that services are becoming a consultation model, where a therapist tells you what you have to do, and you go away and do it. There is less one-to-one support, and little or no monitoring. For some this is an insufficient model. There is also the need for parental training for that support which is offered in the classroom, and doesn't translate as well to home settings. It was suggested this is where the DECLO role could help in ensuring wrap around on all the services. .

58. There is a need for more general training, it was highlighted that teachers will only do one day on additional learning needs as part of their teaching training.

59. We were also told that the right things are not being measured. Waiting lists can be massaged, and often drive people into silos, where they are focused on meeting the targets rather than delivering joined up services. Also this has led to the growth of management at the expense of clinical care, there is a huge management infrastructure at the expense of the services that are supposed to be delivered.

60. There was a feeling that the size of Wales provides an opportunity as it's small enough to develop a consensus on how to improve, and then deliver improved services. We were told Wales "has to be brave, change tack and start listening to families about the hardship."